Being towards death and dying: an interpretive phenomenological exploration of death and dying conversations.

Alexandra Pinto

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The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others.

Assertion of moral rights:

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Abstract

Background

Within Western societies, conversations about death and dying are mainly taboo unless a person is bereaved or facing a life-shortening illness. While psycho-social theoretical conceptualisations of death and dying are offered, little is known about the experience of death and dying conversations amongst adult communities.

Aim

To explore the lived experiences of people's conversations about death and dying.

Method

Drawing on Findlay's relational phenomenology and van Manen's lifeworld existentials, an interpretive phenomenological approach was adopted. Participants were recruited from three groups:1)Stakeholders within the death positivity movement; 2) Adults with a life-shortening illness; 3)Adults without a life-shortening Illness. Data was collected using focus groups and individual interviews and analysed using reflexive thematic analysis to organise the data.

Findings

Twenty-five people participated. The themes identified the multi-dimensional facets that shaped participants' perceptions of death and dying conversations. Findings linked to four lifeworld existentials: 1) Spatiality is essential for creating supportive environments for addressing end-of-life matters constructively and compassionately; 2) Temporality in the context of death and dying can foster resilience, acceptance, and a sense of continuity in the face of life's inevitable transitions; 3) Corporeality fosters a culture of empathy and authenticity in which individuals feel empowered to share their emotions and experiences; 4) Relationality highlights how our relationships with the self and others impact on our readiness for death and dying conversation

Conclusion

In the post-pandemic era, while we are more death-aware and want to engage in narrative support, meaning making and legacy leaving to guide our relational bereavement journeys, conversations about death and dying remain challenging both within and outside of clinical settings. An open approach to death and dying conversations, embracing culturally appropriate terminology, knowledge of human development, creativity and eclectic spirituality, should guide future intervention development.

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Definitions

For the purpose of this thesis, the following definitions will be used:

Palliative Care: “The World Health Organisation has defined palliative care as follows: Palliative care is an approach to care that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten nor postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patient’s illness and in their own bereavement; uses a team approach to address the needs of patients and their families; enhances the quality of life and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, and includes those investigations needed to better understand and manage clinical complications. Palliative care can be provided by a range of health and social care staff and may be done alongside treatment intended to reverse particular conditions.” (NHS Learning Hub, 2021, p. 38).

End-of-Life: “Patients are ‘approaching the end-of-life’ when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with a) advanced, progressive, incurable conditions; b) general frailty and co-existing conditions that mean they are expected to die within 12 months; c) existing conditions if they are at risk of dying from a sudden acute crisis in their condition; d) life-threatening acute conditions caused by sudden catastrophic events. In General Medical Council guidance, the term ‘approaching the end-of-life’ also applies to those extremely premature neonates whose prospects for survival are known to be very poor and to patients who are diagnosed as being in a persistent vegetative state (PVS) for whom a decision to withdraw treatment may lead to their death.” (NHS Learning Hub, 2012, p.38).

Life-shortening condition: “A terminal illness is a disease or condition which can’t be cured and is likely to lead to someone’s death” (Marie Curie, 2021).

List of terms/glossary

Advanced directives: also known as advanced care directives or living wills are legal documents that allow individuals to specify their medical treatment and end-of-life wishes if they become incapacitated and are unable to make decisions for themselves. Advanced directives outline the types of medical interventions a person does or does not want, such as resuscitation or organ donation.

Ancestor veneration: a cultural practice in many societies that involves paying respect and homage to deceased family members or ancestors. It is rooted in the belief that the spirits of the ancestors can influence the lives of the living descendants and often includes rituals such as offerings, prayers and ceremonies to honour and seek guidance or blessings.

Assisted dying: refers to a situation when a person who has a life-shortening illness receives assistance from a medical professional to end their life. This may include providing medication or other means for the individual to self-administer to hasten death.

Assyrians: an ancient civilisation in Mesopotamia known for their military processes and advanced warfare tactics. Their empire spanned from the 25th century BCE to around 612 BCE. They developed a highly organised administrative system, built massive palaces with intricate bas-reliefs, and contributed to agriculture and culture. They also made advancements in literature, maths, and astronomy.

Babylonians: an ancient civilisation that succeeded the Sumerians in Mesopotamia. They were known for their contribution to maths, legal codes establishing laws and punishments for various offences, and astronomers and astrologers.

Buddhism: a religion and philosophical belief system that originated in ancient India around the 5th Century BCE. Founded by Siddhartha Gautama, known as the Buddha. Buddhism is based on his teachings and insights into the nature of suffering and the path to liberation. Key concepts include the Four Noble Truths, the truth of suffering, the cause of suffering, the cessation of suffering and the path to the cessation of suffering. The Nobel Eightfold Path, correct understanding, thought, speech, action, livelihood, effort, mindfulness and concentration. Buddhists seek to achieve nirvana (enlightenment) by following the teachings of the Buddha.

Confucianism: a philosophical and ethical system based on the teachings of the Chinese philosopher Confucius, who lived during the Zhou dynasty. Confucianism emphasises the importance of moral values, filial piety, social harmony and the cultivation of virtue in individuals and society.

Contemporary Western: present-day culture, trends and values of Western societies.

Daoism, also spelt Taoism, is a philosophical and spiritual tradition that originated in ancient China and is attributed to Laozi. It emphasises living in harmony with the Dao, which can be understood as the universe's natural order. Key concepts in Daoism include wu wei (non-action or effortless action), the balance of yin and yang, and the pursuit of simplicity and spontaneity.

Euthanasia: is the act of intentionally ending an individual’s life to relieve suffering, possibly due to a life-shortening illness or unbearable pain. It can be voluntary, where the person who is ill can request assistance to die, or involuntary, where the decision is made by someone else.

Hinduism: is one of the oldest and most diverse religious traditions in the world. Originating in the Indian subcontinent. It includes a wide range of beliefs, practices, rituals and philosophies. The key concepts are karma (the law of cause and effect), Dharma (righteous duty), reincarnation and moksha (liberation from the cycle of birth and death). It included many gods and goddesses, such as Brahma, Vishnu, Shiva, and Devi.

Memento mori: Latin meaning "remember that you must die." It is a reminder of human mortality and the transient nature of life. This concept has been used in art, literature, and philosophy to encourage reflection on the inevitability of death and to inspire a deeper appreciation for life, the present moment, and the importance of living with purpose and mindfulness. "Memento mori" serves as a philosophical and spiritual reflection on the impermanence of life and the need to focus on what truly matters.

Mesopotamia: an ancient region located in present-day Iraq and parts of Syria, Turkey and Iran. It is often referred to as the cradle of civilisation as it is one of the earliest known civilisations in human history.

Plato: a classical Greek philosopher who was a student of Socrates and the teacher of Aristotle. Known for contributions to the fields of philosophy, metaphysics, epistemology, ethics and political theory.

Polytheistic: a belief system that worships multiple gods or deities. In polytheistic religions, such as ancient Greek, Roman, Hindu, and Norse traditions, there are numerous gods and goddesses, each with specific roles, attributes, and domains. Followers of polytheistic faiths may worship different deities for various aspects of life, such as love, war, fertility, wisdom, and nature.

Reincarnation: the belief that after death, the soul or spirit is reborn into a new body. This concept is found in various religions and spiritual traditions such as Hinduism, Buddhism, Jainism, Sikhism, and some New Age beliefs that the soul has multiple lifetimes. Each lifetime offers opportunities for spiritual growth, learning, and the resolution of karma. Reincarnation is often viewed as a way for the soul to evolve and progress towards higher states of consciousness or enlightenment.

Samsara: is a concept in Hinduism, Buddhism, and other Indian religions that refers to the cycle of birth, death, and rebirth. It is the continuous process of reincarnation, in which you move through various states of existence based on your karma (actions) from past lives. The goal in these traditions is to break free from the cycle of samsara by attaining liberation (moksha or nirvana), which is the ultimate spiritual goal to transcend suffering and achieve enlightenment.

Spiritual transcendence: is the experience of going beyond the ordinary, physical, or material aspects of existence to connect with a higher or divine reality. It involves moving beyond the limitations of the self or ego to experience a deeper connection with the universe, God, or a higher power and can lead to feelings of unity, peace, joy, and a sense of oneness with all creation.

Stoic: a philosophy founded in ancient Greece, developed by philosophers such as Zeno of Citium, Epictetus, and Seneca. Stoicism teaches the development of self-control, fortitude, and virtue as a means of overcoming destructive emotions and finding inner peace. Key principles of Stoicism include focusing on what is within one's control, accepting the natural order of the universe, practising mindfulness, and cultivating resilience in the face of adversity. Stoics emphasise the importance of living in accordance with reason, virtue, and nature to achieve a state of tranquillity and contentment.

Sumerians: The Earliest known civilisation in Mesopotamia dates to around 4500 BCE. The Sumerians are credited with the first forms of writing, developed advanced agricultural techniques, and established city-states with sophisticated political and social structures. They also had a pantheon of gods and goddesses with a rich mythology that influenced later Mesopotamian cultures.

Vlogging: a form of blogging that involves sharing video content online. People record themselves discussing various topics, sharing experiences, and offering advice. It allows individuals to connect with audiences through visual storytelling.

Chapter 1
Introduction

"Analysis of death is not for the sake of becoming fearful but to appreciate this precious lifetime." **-** *Dalai Lama.*

This thesis explores the perceptions and experiences of conversations about death and dying. This chapter starts by addressing the psychology of death and dying, highlighting concepts associated with this phenomenon, including taboos and fears. The acceptance of death and dying, as reported in the literature, is also explored, considering different perspectives, contexts, and world views. The origins of the death positivity movement, which promotes activities to support death and dying openness, will be presented. The impact of the COVID-19 pandemic is highlighted in relation to how this unique period led to death and dying, becoming a conversational experience for all. A brief overview of three theories that help explain the psychology of death and dying is provided to provide some theoretical understanding of the focus of the thesis and the study undertaken. Finally, details of the aims of the thesis, along with a thesis overview, will be provided.

1.1 Impetus for study

Death is an absolute reality, but historically, within Western/developed societies, individuals and families have avoided conversations around death and dying; some scholars have argued that this has resulted from the medicalisation of death (Borsatto et al., 2019; Hall, 2019). Often, the topic of death is not discussed until a person is bereaved or facing a life-shortening illness (Dying Matters, 2024). In 2018, a UK national survey of attitudes towards death, dying and bereavement found that even though many people have faced the death of a person close to them, only 7% were comfortable talking about death, and 29% reported they were uncomfortable when the topic of death arises (Co-op, 2018). The survey found young adults (16-29 years of age) were the least comfortable with discussions about death. In contrast, people aged 60-79 were the most comfortable (Co-op, 2018). This suggests a potential generational difference that our theoretical knowledge of human life development could explain. Beyond middle age, it is suggested that we become more focused on generativity because of our proximity to death (Sigelman & Rider, 2012).

Our perceptions and experiences of death and dying are complex and involve biological, psychological, spiritual, societal and cultural factors (Kastenbaum, 2000). Death experiences can define personal meaning and purpose and affect lives (Neimeyer, 2005; Tomer, 2000; Wong, 2008; Kukla et al., 2022). The meanings associated with death and dying are created through observation and experience, which can be attached to objects or events, provoking negative or positive emotions. Negative perceptions of death and dying can create a feeling of powerlessness, loneliness, and meaninglessness. This negativity can lead to distress, existential angst, regret, loss of self-esteem, maladaptive coping strategies, and the development of mental health illness (Huang & Wyer, 2015; Iverach et al., 2014). Conversely, accepting death does not need to lessen life experiences (Wong, 2008). For example, contemporary Western studies have found that having a positive attitude allows growth and motivation to achieve life goals and find meaning (Wong, 2008, 2011, 2012, 2017; Wong & Tomer, 2011).

1.2 My interest in death and dying conversations

I have experienced many forms of loss: loss of career, loss of children and the loss of possible futures. From these losses, my perspective towards death and dying has evolved. Mid-life, I undertook a significant career change and began working within the care industry, specifically as a palliative carer. My role included visiting people at home and supporting the people who wanted to die at home and their families through the end-of-life process. On reflection, I found that this role reinforced my way of living. Death no longer scared me, and I was able to discuss the subject of death without feeling anxious or inhibited. The lessening of my anxiety came about as I saw death or dying daily, with death becoming accepted as a natural part of life. I realised that nothing changes the inevitable and that death is part of everyone's life journey. Understanding that death does not discriminate between young and old has engendered a personal philosophy that I should make the most of the here and now. I began to enjoy what was around me and not worry too much about the future.

During my time as a palliative carer, I became aware that most of the people around me, outside of the work environment, appeared reluctant or unable to discuss death and dying. I observed how people interacted with each other on matters of death and dying in a new way, such as awkwardness when talking to someone who had a loss. People behaved differently when death and dying were part of the conversation. Death is something that I do not fear; it is a part of my life. That does not mean I want to die right now, but rather, I understand and accept it will happen at some point, but until then, I will enjoy every moment.

I have witnessed death among people of all ages, cultures, and religions. Death does not discriminate; it is inevitable. However, as much as my role was rewarding, I wanted to do more, but the direction I needed to take, e.g. medical or counselling, was unclear. Having observed many different reactions to death within my role prompted me to think about people's behaviours and why they react in the way they do. This need to understand more about the psychology of death and dying resulted in me studying psychology as a mature undergraduate student at the University of Bedfordshire. During my studies, I found a passion for research and a desire to understand people's cognitive processes and behaviours throughout their lifespan. In other words, what causes individuals to react to similar situations in entirely different and contrasting ways. For my undergraduate dissertation project, and because of my interest in how people respond to death, I interviewed people who had attended my local Death Café. The interviewed individuals described feeling happier, uplifted, and empowered by attending these cafes. I found this fascinating, in that how can talking about your mortality or any aspect of death make you feel good. It also strengthened my belief in living in the moment, enjoying what I have in the present, as nothing is guaranteed. Having completed a BSc (Hons) in Psychology, Counselling and Therapies, I wanted to continue researching people's perceptions of death and dying.

I undertook an MRes, which explored individuals' perspectives of death and dying to understand the different perspectives and meanings people attach to the topic. I began to appreciate that, generally, people do not have conversations about death and dying until the end of a loved one's life or until they are diagnosed with a life-shortening illness. These findings compelled me to undertake PhD studies, in order to explore people's conversations about death and dying, where they engage in these conversations, what facilitates these conversations, and what are the barriers to preventing them in greater depth; in essence, what is the lived experience of death and dying conversations?

1.3 Death and dying

From a pathophysiological stance, death is the ‘absence of vital functions’ (Tomoasini, 2012; Starr et al., 2024). There are several medical definitions of death. Brain death is defined as the end of all electrical activity within the brain (Machado, 2010; Starr et al., 2024). This definition can be confusing as a person without brain function may still be breathing and kept alive through machinery (Bernat & Larriviere, 2014; Sarbey, 2016). Clinical death is the absence of breathing or circulation/pulse (Malamed, 2015). Biological death is when cells become permanently damaged, usually due to a lack of oxygen (Malamed, 2015). While these biomedical definitions differ, the focus is on the failure of systems that sustain life.

In contrast, Plato defined death as separating the soul and body, believing that the soul was immortal and would continue to exist after death through reincarnation or moving to an afterlife (Davies, 2005). Plato believed in a higher reality beyond the physical world. These definitions are complex; for example, in a Western context, there is an appreciation of both the biomedical and philosophical definitions of death and how these factors intertwine with religious and spiritual belief systems (explored further in section 1.4). Each definition will impact an individual’s attitudes and behaviours and how they ascribe meaning to death and dying.

1.4 Philosophical concepts in relation to death and dying

Death can be perceived as not the end but the beginning of a new life, which may result in a better acceptance of the phenomenon. Religion, faith or spirituality may assuage the fear of death by providing meaning and hope. Therefore, religion, faith and/or spirituality can be essential in a person’s acceptance of mortality (Ando et al., 2010; Harding et al., 2005; Piotrowski et al., 2020). Religious beliefs may impact the individual’s perception of death and mortality, as highlighted by several studies (Jackson et al., 2018; Harding et al., 2005; Piotrowski et al., 2020). The belief that death is not ‘final’ provides a positive perspective of death. For others, death may evoke feelings of fear of retribution or guilt. Regardless of religious beliefs, death is perceived as the end of physical life or the beginning of a spiritual life.

1.4.1 Death and dying in ancient times

In ancient times, death was seen as a transition to another world. Following death, there was a transformation from the mother/hunter role in life to protector/ghost in another world (Kellehear, 2007). For many, there was the belief in the existence of only one God; for example, followers of monotheistic religions such as Christianity, Islam, and Judaism believed in the worship of this single deity. Beliefs about death were intertwined with religious, spiritual and cultural practices (David, 1998). For example, ancient Egypt believed in an afterlife where the soul, or ka, travelled to the underworld, where the judgement was passed (David, 1998). Mummification was used to preserve the body for the afterlife. This reflected the importance of physical integrity in death, with elaborate structures created for the body to be interred. In addition, the Book of the Dead, which included goods, spells, incantations, and inscriptions, provided instructions for the journey to Osiris, the god of the dead (Budge, 2021).

The Mesopotamian, Sumerian, Babylonian, and Assyrian cultures held different beliefs about death. These cultures were influenced by polytheism, the belief in more than one God (Sommer, 2011). The Epic of Gilgamesh, one of the oldest known literary works, discusses themes of death, mortality, grief, and the quest for immortality. Like the Egyptians, the Mesopotamians included goods and offerings with the deceased, and these rituals were undertaken to aid the journey to the underworld (George, 2003). Death was viewed as transformative, a new existence where the soul would face judgement and eternal consequences (Sommer, 2011). In Greece, mythology, philosophy, and religious practices shaped an understanding of death. The afterlife was believed to be governed by Hades, the God of the underworld, and his queen, Persephone (Graves, 2014). Central to their beliefs was that the soul undergoes judgement based on its deeds in life. In his writings, Plato explored the notion of the soul, proposing ideas of reincarnation and the soul's immortality (Retief & Cilliers, 2006). The deceased were honoured by rituals, such as cremation, burial, and commemoration. This ensured a peaceful journey to the underworld (Retief & Cilliers, 2006).

Beliefs in China were influenced by Confucianism, Daoism, and ancestor veneration (Hsu et al., 2009). Death was seen as a natural part of the cosmic cycle, with the journey part of the ancestral realm. Families would honour the deceased with ancestor worship, ancestral tables and rituals. In addition, their view of death was shaped by the concept of *qi,* the life force, along with the balance of *yin and yang*, complementary opposing forces that shape life. (Hsu et al., 2009). The Taoist tradition provided spiritual transformation and immortality teachings and emphasised the cyclical nature of existence and the interconnectedness of all beings (Hsu et al., 2009).

Indian religions, such as Hinduism and Buddhism, have complex belief systems centred on the relationship between death, karma and rebirth (Chetan, 2021). In Hinduism, the cycle of samsara, or reincarnation, governs the soul's transitions through multiple lives based on karma and the actions of past existences (Hinduism Today, 2019). The Bhagavad Gita is central to Hinduism's beliefs about death, a sacred text that explores duty, righteousness and the nature of the soul (Chetan, 2021). Buddhism offers a unique perspective on life, emphasising impermanence, suffering and the quest for enlightenment. Buddhist teachings are guided by concepts of nirvana, liberation, and the cycle of birth and death (Prasad, 2022). The Tibetan Book of the Dead provides instructions on navigating the temporary, transitional state between death and rebirth (Coleman & Jinpa, 2006). Tibetan Buddhist practices include sky burials and rituals that aid the soul's journey to the afterlife, the reflected beliefs in the transitory nature of life and the interconnectedness of all beings (Coleman & Jinpa, 2006). These ancient beliefs about death offer diverse cultural, religious, and philosophical perspectives on mortality. From the elaborate funerary practices of Egypt to the reincarnation teachings of Hinduism and Buddhism, different cultures respond to death through the afterlife, myth, ritual, and spiritual enquiry. From these beliefs, valuable insights can be gained into the human quest to understand the nature of existence, the meaning of death and the possibilities of transcendence beyond the physical realm.

Within the Stone Age era, death tended to be sudden and violent from fatal hunting/foraging accidents or attacks from animals (Gat, 1999; Klein, 1999; Lucas, 1996; Kellehear, 2007). When man stopped wandering the lands and began to settle into small communities and farmed the land (Lewin, 2005; Byrd, 1994; Rosen & Rivera-Collazo, 2012), death was no longer sudden and unexpected. It has been suggested that people could 'see' death coming and, by anticipating death, could prepare for it. At this time, the family and the community would be responsible for actions following the death of a family member, such as laying out the body and organising the funeral (Howarth, 2007). Death was often viewed through a religious lens, with a strong focus on the judgement and the soul's destination in the afterlife. However, as communities evolved into larger towns and cities, there was a shift in how death was managed (outlined in the section below), and perhaps death became less significant in society in the 17th/18th century (the Enlightenment era). Gatherings were reduced, last rites were shared less with the community, and a sense of values was lost.

1.4.2 Death and dying in and beyond the 20th century

There was a shift in people's attitudes towards death and dying in the 20th century. Families had loved ones who had been killed in violent and unnatural ways during two world wars (Jupp & Gittings, 2001; Jalland, 1996; Winter, 2003). The elaborate funerals that were typically staged no longer felt appropriate; bodies could not be repatriated (Jupp & Gittings, 2001; Jalland, 1996). Instead, society created civic memorials and monuments to commemorate those who have lost their lives. The loss of societal norms and traditions diminished, and individuals appeared insecure about how to deal with death. Following the expansion of modern Western society following the Second War, it became a more urban and secular way of life. There appeared to be a significant loss of community rituals (Parks & Prigerson, 2009).

Where before, people would accept death as God's wish, their perception of death began to shift, and some perceived death as an ailment, perhaps something to be cured. Doctors replaced the clergy at the bedside, and as such, death became sequestered (Howarth, 2007). Where communities once were part of the death process, it was now hidden away in hospitals and institutions. Thus, dying for many has become very private and invisible, making it a subject of fear (Howarth, 2007; Jalland, 1996; McConnell et al., 2012; Bifulco et al., 2018). Individuals began to turn to the services of professionals such as doctors, lawyers and funeral directors to deal with death and dying (Howarth, 2007; Kellehear, 2007; McConnell et al., 2012; Bifulco et al., 2018). Religion can often provide comfort and meaning in the face of death anxiety by offering beliefs about an afterlife and purpose. However, relying solely on religious beliefs to cope with death anxiety may limit a person's ability to fully explore and understand their feelings (Rybarski et al., 2023). Moving beyond this reliance on religion can involve seeking a range of support sources such as therapy, philosophy, or personal reflection to develop a more comprehensive understanding of death and its place in the world. Having a broader perspective of death can lead to a more nuanced and enriched approach to dealing with death anxiety.

1.5 Taboos, fears, and acceptance of death and dying

Death is an event that touches every living being, and the fear of it is a complex part of existence. Death can be viewed through various lenses, such as psychology, religion, philosophy and culture. The uncertainty and finality of death can cause fear and challenge our sense of self, purpose and existence (Pyszczynski et al., 1997; Pyszczynski et al., 2015; Routledge & Vess, 2018). The primal instinct for self-preservation and survival ingrained in consciousness may be at the heart of this fear. According to the field of psychology, fear serves as a survival mechanism to avoid harm and safeguard and ensure the continuity of life (Greenberg et al., 1986; Pyszczynski et al., 2015; Routledge & Vess, 2018). The fear of death is closely intertwined with the fear of the unknown since death symbolises an enigma beyond understanding. The existential philosopher Heidegger characterised death as the possibility that uncovers the finitude and impermanence of human existence, compelling individuals to confront their mortality and the transient nature of existence (Heidegger, 2010).

1.5.1 Death Anxiety

Freud’s work on psychoanalysis and death (Kahn & Liefooghe, 2014; Kli, 2018) resulted in a belief that people had two primary forces: the life instinct (Eros) and the death instinct (Thanatos). Eros refers to life drives such as procreation, social cooperation and survival instincts (Capuzzi & Stauffer, 2016; Kli, 2018). In contrast, Thanatos refers to the primal, instinctual urge towards self-destruction and the return to an inorganic state. This concept can be linked to death rituals and cultural defences as they can be related to ways to manage and channel these destructive impulses (Kli, 2018). Death rituals, such as funerary practices and mourning customs, provide structured ways for individuals and societies to cope with loss and express grief, thereby containing and giving meaning to the destructive aspects of Thanatos. Cultural defences, such as religious beliefs or societal norms around death, can also serve to mitigate the anxiety and fear associated with mortality by providing frameworks for understanding and accepting the inevitability of death.

Ernest Becker, a cultural anthropologist, proposed the concept of ‘death anxiety’ as a fundamental aspect of human psychology. His book, ‘The Denial of Death’, explores how individuals construct symbolic defences and cultural worldviews to manage the terror of their mortality (Becker, 2020).

> “*Never before have people died as noiselessly and hygienically as today in the societies, and never in social conditions so much fostering solitude*”. (Elias 2001, p.p.85).

The way different cultures view death significantly impacts how people perceive and experience the fear of dying. Ceremonies such as funerals, prayers, and memorials create moments for grieving, honouring memories and showing respect to the departed. These ceremonies can foster a sense of connection that transcends passing (Reeves, 2011). In some traditions, for example, Mexico’s Day of the Dead (National Geographic Society, 2012), the dead are celebrated as part of life. Deceased ancestors are honoured, and death is embraced as an integral aspect of the human experience. In contrast, the medicalisation of death has contributed to a sense of anxiety, fear, and disconnection from the natural process of dying (Borsatto et al., 2019; Hall, 2019).

Philosophical inquiries into the fear of death have identified diverse perspectives on mortality, consciousness, and the human condition (Moore & Williamson, 2003). Existentialist thinkers like Sartre and Camus pondered the lack of meaning in life when facing death, advocating for freedom, accountability and authenticity amidst angst (Sartre & Camus, 2004). Stoic beliefs offer teachings on embracing death with grace, developing resilience, and acknowledging death as a part of the universe order (Inwood, 2018; Sellars, 2020). By facing the fear of death through introspection, insights can be gained into life's impermanence and the importance of living and seizing opportunities in the present moment.

1.5.2 Death acceptance

Culturally, acceptance of death is evident in customs, traditions and rituals that honour the departed, commemorate ancestors and recognise the cycle of life and death (as discussed in section 1.4). Practices worldwide include ceremonies for mourning, grieving, and acknowledging the interconnectedness of all living beings within the cycle of life and death. Individuals can nurture a more profound sense of acceptance of mortality by participating in traditions that normalise death. Spiritual viewpoints on accepting death draw from beliefs, mystical wisdom teachings and meditative practices. These provide insights into existence, cognition and the soul's transcendent journey post-death.

Many belief systems offer stories about life after death, rebirth or spiritual enlightenment. These stories bring comfort, hope and significance when faced with mortality. Engaging in meditation, prayer, and mindfulness can help people develop a sense of being present, connected and at peace amidst life's uncertainties (Timbers & Hollenberger, 2022; Jackson et al., 2018; Harding et al., 2005; Piotrowski et al., 2020; Boles & Jones, 2021; Koenig et al., 2012; Clarke et al., 2013). Individuals can enhance their acceptance of death by contemplating questions about purpose, meaning and spiritual growth (Wong & Tomer, 2011; Molamohseni et al., 2024). This transformative process can challenge individuals to navigate emotions, beliefs, and existential uncertainties (Wong & Tomer, 2011; Molamohseni et al., 2024). Feeling grief, sorrow, and existential anxiety is a response when contemplating mortality. However, these feelings can also trigger growth, self-discovery, and resilience. By confronting the fear of death head-on, exploring questions about existence, and accepting life's impermanence, individuals can foster an acceptance beyond fear or avoidance. This reflective consciousness can lead towards peace, clarity, and authenticity in the face of mortality.

1.6 Death perspectives in current contexts

Perspectives on death incorporate many of modern society's beliefs, attitudes, and practices, such as viewing death as a natural part of life. Religion and cultural beliefs provide comfort and meaning towards quality of life, end-of-life care, and open conversations with loved ones. With technological and medical advancements and changes in cultural norms, the way death is approached and viewed is an ongoing evolutionary process. These advances can impact approaches to the care of those dying, such as palliative care, assisted dying, the digital era and pandemics, as outlined below.

1.6.1 Palliative and end-of-life care

Significant medical advancements in the last few decades have included new therapies and technology that have prolonged life expectancy. Consequently, there has been a growing focus on providing quality care for those facing their final stages of life. The underpinning philosophy of hospice and palliative care is a holistic approach to meeting individuals' physical, emotional, and spiritual needs with a life-shortening illness (Wajid et al., 2021). Palliative care is a specialised type of medical care focused on symptom management and aims to improve the quality of life for patients and their families (WHO, 2024). This is achieved by addressing the physical, emotional, social and spiritual needs. Teams of healthcare professionals work together with the patient to manage pain, control symptoms and offer support and guidance with treatment options/decisions. Palliative care is often provided alongside illness-specific treatments and is not dependent on prognosis.

End-of-life care is the support and medical care given during the final stages of a life-shortening illness or nearing the end-of-life. This type of care focuses on ensuring patients' comfort, dignity, and quality of life as they approach death (NHS, 2024a). End-of-life care, similar to palliative care, includes pain management, symptom control, emotional and spiritual support, help with personal care and guidance for patients and their families in making decisions about treatment options, and advance directives and palliative care. The ultimate goal of end-of-life care is to help individuals have a peaceful and comfortable death.

1.6.2 Assisted dying/euthanasia

Death anxiety is a fundamental aspect of human existence that influences individual behaviour and societal structures. Cultural and social psychology play crucial roles in shaping how individuals, cultures, and groups perceive and respond to assisted dying. Cultural beliefs, norms, and rituals surrounding death can provide frameworks for understanding and coping with mortality, influencing individual attitudes and behaviours towards death (Jackson et al., 2018; Harding et al., 2005;

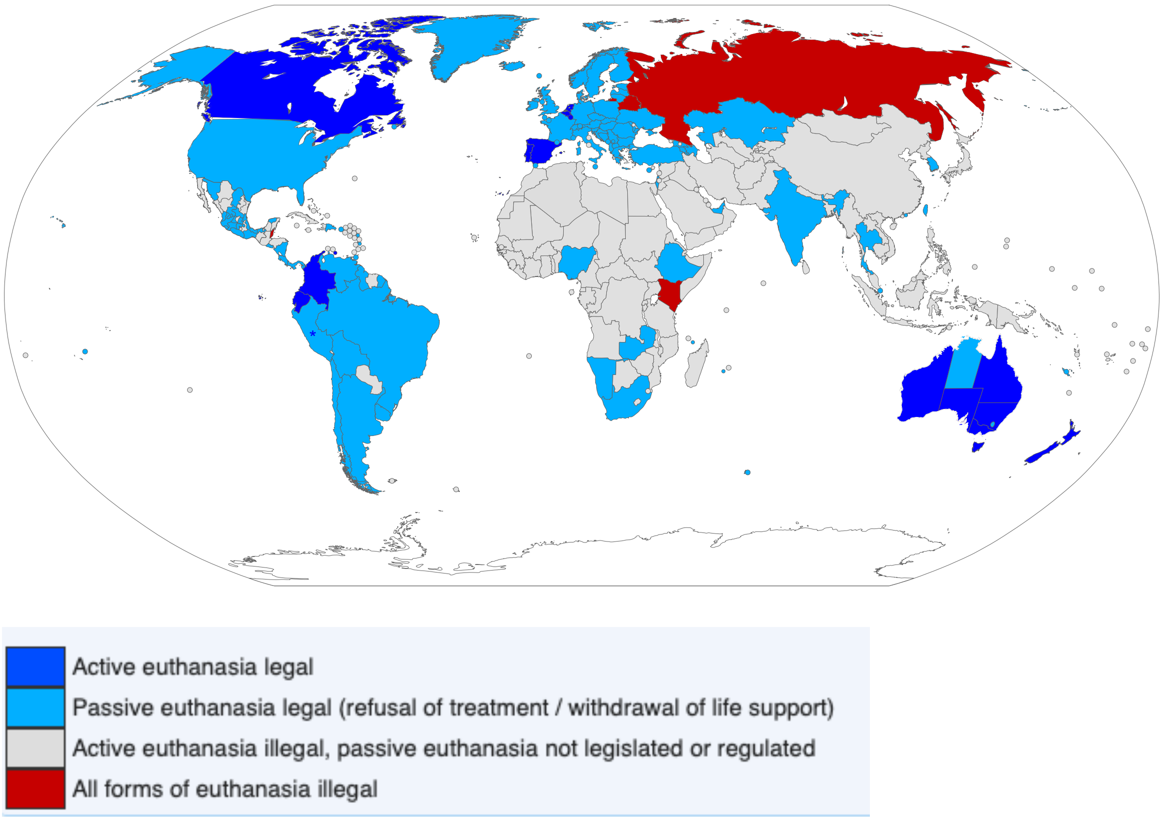
Piotrowski et al., 2020). Social psychology examines how social influences, group dynamics, and interpersonal relationships impact how individuals experience and express death anxiety within their communities (Auger, 2019). By understanding the intersection of assisted death with cultural and social psychology, we can gain insights into how individuals and societies navigate the complexities of mortality and develop coping mechanisms to address the ethical implications of assisted dying practices within a cultural and societal context.

For some with a life-shortening illness, palliative care may not be an option they wish to pursue, and they may want to end their lives on their own terms. Currently, there is a growing movement within the UK to legalise euthanasia.

The ongoing debates about euthanasia in Western societies are highly emotive and typically centre on ethical, legal, and moral dilemmas. Many countries, such as Oregon, Washington, California (USA states), Canada, Switzerland, New Zealand, Australia, Belgium, Luxembourg, Netherlands, and Spain, have legalised euthanasia. The law has yet to be in force in Portugal and is awaiting regulation (Figure 1.6.2). For complete information regarding physician-assisted dying legislation around the world, please access https://www.bma.org.uk/advice-and-support/ethics/end-of-life/physician-assisted-dying

Figure 1.6.2

Countries showing passive, current and partial availability of euthanasia



In England, debates are currently being held in the Houses of Parliament to consider changes to the law about assisted dying. In Scotland, a bill has been proposed seeking approval to legalise euthanasia. Supporters of euthanasia argue that individuals should have the autonomy to choose a dignified death when facing a life-shortening illness. However, there is a counterargument that individuals may be pressured into euthanasia for the personal gain of loved ones/family. In addition, there is a lack of understanding of quality palliative and end-of-life care, which can impact decisions on euthanasia (Dignity in Dying, 2024).

1.6.3 Death and dying in a digital age

Many people throughout the world will have some form of digital footprint, which is transforming how we grieve and deal with death and dying. Online memorials, social media tributes and virtual support networks provide new avenues for remembrance and connection (Beaunoyer & Guitton, 2021; Asgari et al., 2022). This new digital world creates a concept of a digital afterlife. Many individuals leave behind a digital footprint that carries on after death. Social media platforms such as Facebook now offer options for memorialising accounts and appointing legacy contacts to manage these accounts. However, continuing social media accounts, email archives, and online profiles pose challenges, morally and ethically, in relation to digital legacy and posthumous privacy, including estate planning, data security, and surrounding someone's online presence after death.

The trend of individuals using digital media to tell their story of their illness is sometimes known as vlogging (Sánchez-Querubín & Van Laarhoven, 2019). Research has shown that individuals have used various online platforms such as cancer blogging (Heilferty, 2009; Keim-Malpass et al., 2012; Wellman et al., 2022) and social networking sites like Facebook (Bender et al., 2011; Erfani et al., 2012, Zhao et al., 2022), Twitter (Sugawara et al., 2012; Tsuya et al., 2014; Vicari, 2020), Instagram (Vraga et al., 2018), and Youtube (Foley et al., 2015; Devan et al., 2021) to express their thoughts and share experiences. Research indicates that the content shared by cancer patients on social media tends to be more experiential and opinion-driven rather than medically focused (Chiu & Hsieh, 2012; Kim & Gillham, 2015), highlighting a desire to discussing the psychosocial aspects of their illness (Keim-Malpass et al., 2013; Ressler et al., 2012, Wellman et al., 2022; Zhao et al., 2022; Vicari, 2020; Devan et al., 2021).

Openly sharing their thoughts and feelings about their mortality may suggest a growing awareness and acceptance of the importance of palliative and end-of-life care in modern society. By documenting their experiences, these individuals are not only providing personal insights into the dying process but also raising awareness about the need for compassionate end-of-life care, open communication, and support for individuals facing a life-shortening illness. This trend highlights the power of storytelling and personal narratives in promoting discussions around death, quality of life, and the significance of dignified care at the end of life.

1.6.4 COVID

The world was exposed to the COVID-19 pandemic in 2020 (World Health Organisation,2020). Consideration must be given to the impact, if any, the pandemic had/is having on conversations about death and dying. During the pandemic, individuals dealt with death both collectively and individually. Families were separated from loved ones at the end of their lives (whether or not COVID-19 related) and faced with questions about their end-of-life wishes (Centre for Evidence-based Medicine, 2020).

Similarly, family members had to deal with advance directives for the first time for individuals who were classed as' vulnerable’. (Centre for Evidence-based Medicine, 2020). COVID forced people to confront death and dying and brought these conversations to the fore.

The uncertainty surrounding the virus, its spread, and the impact it had on health and daily life led to increased levels of anxiety and fear (Garfin et al., 2020). Death and dying entered every household via some form of news or social media updates (Cinelli et al., 2020). There were lockdowns, social distancing measures and quarantines that increased loneliness and social isolation. During the pandemic, mortality rates worldwide increased (Mathieu et al., 2020). The rapid spread and the overwhelmed healthcare systems posed challenges in providing adequate end-of-life care and support for those who were dying (Jeleff et al., 2022; Mohammadinia et al., 2023). There was a shortage of resources and concerns about infection control for patients requiring patient care, whether Covid or non-Covid related, as well as the allocation of resources and triage protocols. This strained the ability to provide compassionate and personalised care to those dying and raised ethical dilemmas surrounding end-of-life decision-making (De Luca et al., 2023; Yip, 2021; Baines et al., 2020). Difficult decisions had to be made by health professionals regarding treatment options, ventilator use and palliative care in the context of limited resources and high demand for intensive care services.

The isolation and separation experienced by patients and their families and the prevention of families being by the side of dying relatives lead to a sense of helplessness, grief, and unresolved emotional issues (Selman et al., 2021). Grieving and death were particularly challenging as people were not allowed to be with their dying loved ones at the end of their lives. The pandemic disrupted the traditional cultural and religious practices that surround death and dying. Funeral ceremonies, burial rites, and memorial services had to be modified or postponed (Lowe et al., 2020). These changes in normal expectations exacerbated feelings of loneliness, sadness, and depression (Cao et al., 2020; Eisma et al., 2020). However, despite these challenges, individuals and communities demonstrated resilience and adaptability to find ways to navigate the loss and grief. There were acts of kindness during this challenging time (Wei, 2023), mutual support (Newman, 2020), virtual memorials (Myers & Donley, 2022), online grief support groups (Morris & Ryan, 2021), virtual counselling (Singh & Sagar, 2020) and community outreach programs (Gilmore et al., 2020; Manikam et al., 2021), which attempted to provide some level of comfort and solace to deal with the emotional impact of the pandemic. However, it is unclear if the heightened focus on death and dying has had a lasting effect on society and individuals' views and discussions about death and dying. Further research is required to understand the impact and potential shifts in attitudes and behaviours regarding death and dying in society.

1.7 Death positivity movement

The death positivity movement is a growing cultural shift that aims to change the way society views and discusses death and dying. Its overall ethos is to encourage open conversation regarding mortality, challenge the taboos surrounding death and dying, and promote the acceptance of the inevitability of death and dying. The movement incorporates death education, end-of-life planning, funeral practices, grief support, and the celebration of life (Order of a Good Death, 2024; Death Café, 2024; Dying Matters, 2024).

The death positivity movement can be viewed as a modern iteration of a social movement that originated in the 1970s, championed by figures like psychiatrist Kübler-Ross (1969), who pioneered the five stages of the grief model; Mitford (1963), who critiqued the funeral industry in America who were profiting from it; Dr Cicely Saunders who pioneered specialist care for the individuals who were dying by focusing on their comfort and mitigating any suffering. These champions challenged the notion that contemporary societies should not shy away from discussions on death, positing that this avoidance of discussing death and dying detrimentally impacts individuals' well-being across all life stages. These pioneers and others advocate for open conversations and active engagement with death and dying conversations, including end-of-life planning, citing numerous benefits. While Lofland (1978) initially criticised the death awareness movement as the 'happy death movement,' the emergence of death positivity has reignited interest in this viewpoint.

Death positivity is deeply intertwined with consumer culture, with discussions on death intertwined with lifestyle choices and identity politics (Koksvik, 2020). Some of the more recent death awareness-raising initiatives are Death over Dinner (Hebb, 2018), Death Cafes (Death Café, 2024), Death Salon (Death Salon, 2024) and Order of the Good Death (Order of a Good Death, 2024). One of the leading pioneers who coined the phrase ‘Death positivity movement’ was Caitlin Doughty, the founder of The Order of the Good Death (OGD) in 2011, which has one goal:

> *‘The Order is about making death a part of your life. That means committing to staring down your death fears—whether it be your own death, the death of those you love, the pain of dying, the afterlife (or lack thereof), grief, corpses, bodily decomposition, or all of the above. Accepting that death itself is natural, but the death anxiety and terror of modern culture are not.’*

Caitlin is an American funeral director who wanted to change how death was viewed. She tried to encourage death acceptance with a return to memento mori, reminders of one’s mortality, which can result in a better relationship with death. John Underwood started the Death Cafes by reading about Bernard Crettaz’s Cafés Mortels. Crettaz’s first Cafés Mortel was held in 2004 in a Swiss town called Neuchâtel, where 250 people lived (Morgan, 2017). Underwood aimed to reclaim death as a natural part of life and offer a space to discuss any aspect of death. The Death Cafés have become a worldwide phenomenon that has reached 89 countries since September 2011 (Death Café, 2024). Research has shown that Death Cafés can promote community-wide literacy around death and loss (Laranjeira et al., 2022), engender feelings of intimacy and connection (Koksvik & Richards, 2023), allow for people to make sense of and identify meaning in death to their own lives and those that are close to them (Miles & Corr, 2017).

One component of the death positivity movement is death education, which involves increasing people’s awareness and knowledge about death and dying and end-of-life care. Educational resources focus on hospice care, palliative care, funeral planning, and grief support. Providing these resources empowers individuals to make informed decisions and have open and frank discussions about death and dying (Dying Matters, 2024). The movement emphasises the importance of providing compassionate and supportive care to grieving people to destigmatise grief and encourage healthy expressions of mourning, such as safe spaces for open conversations about loss, offering counselling and bereavement services, and promoting community support networks.

The death positivity movement encourages individuals to be proactive with their end-of-life planning. This is achieved by creating advance directives, discussing wishes for medical care, and making funeral arrangements. By being proactive and addressing these issues, individuals can ensure their choices are honoured and provide relief for their loved ones from the burden of making difficult decisions during a very emotional period (Dying Matters, 2024). In addition to end-of-life planning, the death positivity movement advocates for alternative funeral practices that reflect the individual's individuality and preference, such as eco-friendly burial options, home funerals, and creative memorial services that celebrate life meaningfully (Order of a Good Death, 2024).

The death positivity movement can have a significant cultural impact by challenging traditional attitudes towards death and dying and promoting a more open and accepting approach to mortality (Wong, 2008). Through social media and literature, the movement has sparked conversations about death that are honest, reflective, and inclusive of diverse perspectives. Many organisations, such as Dying Matters, are part of the death positivity movement and have undertaken extensive national surveys (Dying Matters, 2024), suggesting that having open, frank conversations about death and dying has a beneficial effect. At present, there appears to be a dearth of empirical peer-reviewed research that supports the benefits of the death positivity movement. However, embracing the principles of the death positivity movement has the potential to benefit individuals and society by gaining a deeper appreciation of life, cultivating resilience in the face of loss, fostering empathy and creating connections and conversations about death and dying with others. To live a more authentic and meaningful life and create a more compassionate and death-informed society that embraces the full spectrum of the human experience.

1.8 Psychological theories of relevance in exploring death and dying conversations

Applying theoretical frameworks can help explain our understanding of the complexities surrounding death positively and conversations about death and dying. Psychoanalytic theories, including those of Freud (Kahn & Liefooghe, 2014; Kli, 2018), Erikson (Sigelman & Rider, 2012), and Klein & Winnicott (Abram &

Hinshelwood, 2018), offer insights into the connections between death anxiety and cultural/social psychology. For instance, Freud’s concept of Thanatos, highlighted in section 1.5.1, illustrates how unconscious desires for self-destruction can influence individual behaviour and societal attitudes towards death (Kli, 2018). Erikson’s psychosocial theory of human development suggests that confronting death is an important developmental task that shapes identity and relationships with others (Sigelman & Rider, 2012). Similarly, object relations theorists such as Melanie Klein and Donald Winnicott (Abram & Hinshelwood, 2018) have explored how early relationships with caregivers can affect an individual’s perceptions of death and loss, thus impacting their capacity to form attachments and manage existential fears within cultural contexts (Abram & Hinshelwood, 2018). These varied perspectives provide a foundation for understanding how cultural and social factors interact with individual psychological processes to shape responses to death anxiety.

Existential theorists such as Yalom and Frankl explored how individuals deal with death anxiety and find meaning in their lives. Yalom postulated the importance of confronting existential concerns, such as death, to live authentically and find purpose (Yalom, 1980). Similarly, Frankl’s logotherapy focuses on finding meaning in suffering, including the existential fear of death (Frankl, 1986).

The terror management theory, developed by Greenberg, Pyszczynski, and Solomon, expanded on in Section 1.8.1, explores how individuals manage the terror of mortality by embracing cultural worldviews and self-esteem to buffer existing anxiety. These perspectives shed light on how individuals navigate death anxiety within cultural and social frameworks, shaping beliefs, behaviours and psychological well-being. However, positive psychology and post-traumatic growth (PTG) can offer insights into how individuals can thrive and find meaning in the face of adversity, including death anxiety, outlined in section 1.8.4. Positive psychology focuses on strengths, resilience and well-being, emphasising the importance of positive emotions, relationships and personal growth (Hefron & Boniwell, 2011; Hart, 2020). PTG, a concept developed by psychologists Tedeschi & Calhoun, suggests that individuals can experience personal growth and transformation following traumatic events, such as confronting mortality or loss (Tedeschi & Calhoun, 1995). In the context of death anxiety, positive psychology and PTG highlight the potential for individuals to develop resilience, find meaning and experience personal growth through their encounters with mortality.

Consideration must also be given to the cultural and social psychology of death and dying. Cultural and social psychology examines how cultural norms, beliefs, and social influences shape individual behaviour and psychological processes (Pyszczynski et al., 2015; Routledge & Vess, 2018). In the context of death anxiety, cultural psychology explores how cultural beliefs, rituals, and traditions surrounding death affect how individuals perceive and cope with mortality. Social psychology investigates how social factors, such as social support, group dynamics, and societal attitudes towards death, influence how individuals experience and express death anxiety within their communities (Pyszczynski et al., 2015; Routledge & Vess, 2018). By integrating cultural and social psychological perspectives, we can gain a deeper understanding of how individuals and societies navigate the complexities of death anxiety, develop coping mechanisms, and construct meaning around mortality. By incorporating these various views alongside cultural, social, psychoanalytical, and existential psychological theories, we can better understand how individuals navigate death anxiety, cope with existential fears, and cultivate psychological well-being in the face of mortality.

This thesis will draw on terror management theory (Greenberg et al.,1986), meaning management theory (Wong 2008) and gestalt theory (Koffka, 2014), the factors influencing individuals' attitudes towards mortality, the societal implications of embracing death positivity, and the potential benefits for mental health and well-being can be explored and explained. This study seeks to apply these theoretical perspectives to elucidate the underlying mechanisms driving death acceptance and shed light on any cultural and social influences on death and dying discussions promoting resilience in the face of morality that may be relevant to the study undertaken as part of this thesis.

1.8.1 Terror management theory

Terror management theory (TMT) is a social psychological theory exploring how people cope with the fear of their mortality. TMT suggests that the unconscious fear of death impacts most human behaviour. This fear, which creates anxiety, can often be offset with self-defence mechanisms by developing cultural worldviews, bolstering self-esteem, adhering to cultural norms and values, striving for symbolic immortality through achievements or offspring, and derogating individuals who challenge one’s worldview (Greenberg et al., 2015; Greenberg et al., 1986; Greenberg et al. 1994; Pyszczynski et al., 2015). Cultural worldviews are when individuals adopt shared beliefs and values within a society, providing a sense of order, meaning, and permanence in the face of mortality. These worldviews can help individuals feel connected to something greater than themselves, reducing the fear of death and providing a buffer against the anxiety of death. From a TMT perspective, the management of death anxiety is governed by socially constructed beliefs that help individuals to have meaning and self-worth. However, when these psychological structures are disrupted, then thoughts of our mortality become more present. Increasing the behaviours that impact self-esteem can help to assuage thoughts of our mortality (Hayes et al., 2008). One of the central tenets of TMT is Mortality Salience, a term created by Greenberg, Pyszczynski and Solomon (1986).

Mortality salience (MS) refers to the psychological state when a person consciously thinks of their death. Research has shown that when MS is manipulated, it can affect the person's behaviour and reaction to others when perceived as a violation or deviation from their shared cultural standards and values (Greenberg et al., 2015). The feeling of being threatened existentially can push people towards activities such as gaining as much wealth as possible (Kasser & Sheldon, 2000), prioritising popularity, self-image and away from goals such as personal growth, community, and contribution (Sheldon & Kasser, 2008). MS is a unique psychological concept that involves a person’s heightened awareness or contemplation of their mortality (Greenberg et al., 1994; Burke et al., 2010). For example, in a study by Rosenblatt et al. (1989), judges reviewed cases and recommended a fine for women who were accused of prostitution. The researchers hypothesised that if the MS was increased, judges would seek to defend their worldview, and judges who thought about their mortality would give harsher fines. Results indicated that the judges reminded of their mortality gave higher penalties than those who had not received any mortality reminders. In addition to MS, self-esteem is also seen as a defence mechanism to the fear of death.

Self-esteem can be described as an individual’s self-worth or personal value. A study by Taubman-BenAri, Florian, & Mikulincer (1999) suggested that when a person’s MS was manipulated, participants’ self-belief in their driving abilities increased, which caused an increase in risky driving behaviours. However, when they were given positive feedback before using the simulator, it reduced the amount of dangerous driving. These results regarding self-esteem and MS manipulation were supported by Peters, Greenburg, Williams and Schneider (2005), Goldenberg, McCoy, Pyszczynski, Greenberg, and Solomon (2000) and Mikulincer and Florian (2000) and Florian and Mikulincer (1998). This research suggests that individuals can find meaning by building their self-esteem, which buffers them from the anxieties of death.

TMT proposes that protecting an individual's cultural worldview is essential in preventing existential angst (Pyszczynski et al., 2015). Culture can define a person's values and beliefs and conformity to societal norms, which may influence thoughts and perspectives of death and dying. The shared view may give meaning, significance and permanence to life, providing a sense of immortality, be that literal immortality, religious afterlives such as reincarnation or heaven, or symbolic immortality, being part of something greater than continues after death (Pyszczynski et al., 2015), for example, a story of a person that continues long after they have died. Individuals may defend and uphold their cultural worldviews more fervently when faced with reminders of death. This type of defence can manifest as an increased adherence to cultural norms, stereotypes and traditions, with individuals exhibiting prejudice or hostility towards those who challenge or differ from their cultural worldview (Pyszczynski et al., 2015). By devaluing outsiders, individuals reaffirm their ingroup beliefs' superiority and validity (Motyle & Pyszczynski, 2009). It is these social constructs that serve as a buffer to the anxiety of death and dying, leading to individuals continually seeking affirmation of the validity within their culture.

Whilst there has been significant empirical support for TMT, it has been criticised in recent years (Martin & van den Bos, 2014; Hart, 2019; Arrowood & Cox, 2020; Treger et al., 2023). Some researchers have argued that TMT is culturally laden and possibly culture-bound (Yen & Cheng, 2013). TMT has been challenged about the definition of self-esteem (Buss, 1997; Navarrete, 2005; Kirkpatrick & Navarrete, 2006). Trafimow and Hughes (2012) examined TMT in relation to the prediction of death through the suppression and rebound hypothesis. The primary aim of Trafimow and Hughes' (2012) study was to examine the prediction of the death thought suppression and rebound hypothesis. According to this hypothesis, thoughts of death are initially suppressed following mortality salience (MS). Subsequently, these thoughts resurface and become more accessible after a delay.

In essence, after being reminded of mortality, thoughts of death are expected to be more accessible with a delay compared to immediately after the reminder, as supported by Kosloff et al. (2019). In addition, van den Bos and Miedema (2000) and van den Bos (2001) have critiqued the mechanisms for why MS leads to its effects. Whereas Klein et al., 2022 failed to replicate some of the primary effects seen within the TMT literature. However, Chatrad, Hirschberger, and Pyszczynski (2020) critiqued Klein's studies for their insufficient sample sizes, failure to follow the researchers' advice and deviation from the preregistered study protocol. Others have failed to replicate the TMT result even while following the methods meticulously (Yen & Cheng, 2010; Chew & Yap, 2021; Sætrevik & Sja˚stad, 2022; Vergani et al., 2019). Schindler et al. (2021) found that the worldview-dependent variable was not strongly found in their studies when they had accounted for publication bias, control conditions and researcher effects. There is still a large body of evidence that supports TMT. However, considerations need to be taken into the demographics, cultural, and societal changes that have occurred in the past few years.

TMT, often associated with the fear of death and dying, also offers a more positive perspective. Positive Terror management theory, an extension of the original TMT, postulated that reminders of mortality can lead to positive outcomes, including increased self-esteem, pursuit of meaningful goals, and prosocial behaviour. The theory posits that the awareness of mortality can serve as a powerful motivator, inspiring individuals to strive for personal growth and contribute to society in meaningful ways (Vail et al., 2012). This optimistic view of the impact of mortality on human behaviour offers a refreshing perspective on a topic often associated with fear and anxiety.

1.8.2 Meaning management theory

Death acceptance, an under-researched field, has garnered attention since the pioneering work of Ray and Najman (1974), who developed a scale to measure death acceptance. However, no further significant research seems to have been undertaken until the late 1980s and early 1990s. Gesser et al. (1988) developed the multidimensional Death Attitude Profile (DAP) scale, which included dimensions of the fear of death and acceptance of death and dying. This scale was revised by

Wong et al. (1994) when they expanded the dimension of fear of death/dying, making it the DAP-R.

The relationship between death acceptance and well-being was investigated by Wong et al. (1994), who theorised that death acceptance had three components:

1. Neutral acceptance: The understanding that death is part of life, inevitable and natural, and neither feared nor welcomed.
2. Approach acceptance: The understanding that death is not the end but a new and better afterlife. There is a belief in some form of God, and the afterlife is seen as a much better place where there is hope that you will be able to see loved ones again.
3. Escape acceptance: Death is perceived as a better alternative to life. Death is seen as an escape from the traumas or hardships and difficulties of life.

Wong (2008) developed a conceptual psychological framework, the meaning management theory (MMT), based on his previous work on death acceptance and positive psychology. Wong argued that meaning in life and acceptance of death are intertwined. The theory focuses on managing inner life, including all hopes, dreams, aspirations, hate, regrets, doubts, and beliefs (Wong,2008). It is based on how an individual attaches meaning to events that happen in everyday life and enables these meanings to create a more fulfilled and meaningful life (Wong & Tomer, 2011). MMT's roots are in the positive psychology movement and existential-humanistic theories, and it incorporates cognitive-behavioural processes such as stress appraisals, attributions, and decision-making to understand human experiences (Wong, 2010). The theory posits that if an individual wants a more meaningful life, they could focus on positivity and personal growth rather than the defence mechanism discussed above in 2.1. MMT is grounded in the central assumption that humans are motivated to survive and find meaning or reason for survival. The theory proposes three underlying processes:

1. Meaning-making: the focus is on the activities followed by the individuals when actively interpreting, building, and creating meanings for their events/situations. This can be achieved through social construction, storytelling, goal striving and personal development.

2. Meaning-seeking: individuals have incredible amounts of information to process daily, and to make sense of it, they need to be able to predict or even control some situations. e.g. operant and Pavlovian conditioning teach individuals the importance of stimuli. This attribution process allows individuals to find cause-and-effect relations (Wong, 1991; Wong & Weiner, 1981). In addition to this, causal attribution is existential, allowing individuals to make sense of adverse events in their lives by trying to see a positive aspect of them (Tomer et al., 2014)
3. Meaning-reconstruction: coping when traumatic events or adversities have changed a person’s world by amalgamating the negative incident into a positive future or event. This can be achieved by confronting the past, reviewing it, examining it, and looking for new alternative meanings (Wong, 2008).

Typically, all three processes work simultaneously to facilitate meaning and death acceptance by increasing the individual's subjective sense of meaning in their lives. Wong (2008) contends that distinguishing between and recognising their distinct impacts on the perception of meaning can lead to more meaningful interpretations of research findings.

MMT predicts that the inclusion of spiritual values and beliefs may protect against the fear of death and help with death acceptance. A quantitative study by Harding et al. (2005) found that the belief in God’s existence and the afterlife were positively correlated with death acceptance. MMT predicts that a sense of meaning and purpose can protect against the fear of death and help more towards well-being than other psychological structures such as internal control and self-efficacy (Wong, 1993, 2005, 2006; Emmons, 1992, 1997). Ardelt’s (2003) quantitative study of the effects of religion and purpose in older individuals found that meaning in life is negatively associated with death anxiety. Moore et al. (2006) found that older people with high scores on meaning in life had a more optimistic approach to death, even while suffering. Research suggests that individuals with a purpose in their lives based on their values perceive death objectively and calmly and experience less anxiety (Moore et al., 2006; Tang et al., 2002; Lyke, 2013; Zhang et al., 2019) suggest a negative correlation between meaning in life and death anxiety, showing that having found meaning in their lives, they were able to accept death. However, individuals who have higher levels of death anxiety may have a lower sense of purpose in their lives, as seen in a quantitative study by Routledge and Juhl (2010).

The distress and struggles that people may face make them seek meaning in their lives, and that meaning is essential for hope and happiness despite any pain they may be suffering (Frankl, 1984). Finding meaning in life and death can help individuals understand their mortality and influence their perceptions of death and dying. Meaning allows individuals to embrace life more fully, regardless of circumstances, adversities or traumatic events (Frankl, 1984).

Religious or spiritual beliefs often provide meaning to individuals, along with frameworks for understanding and accepting death (Harding et al., 2005). Living fully can enhance relationships with others and the sense of self and well-being (Wong, 2008). Developing healthy coping mechanisms can aid in accepting the inevitability of death, along with increasing knowledge about death and dying processes to reduce fear and promote acceptance. Therapy, counselling, support groups and leaving legacies are all tools and strategies to facilitate death acceptance. The best way a person could reduce their anxieties about death is to facilitate death acceptance, live a more meaningful life, and focus on the positive tendencies of personal growth as a way to deal with death anxieties (Wong, 2008; Wong & Tomer, 2011).

1.8.3 Gestalt theory

Wertheimer, Koffka, and Köhler identified six principles associated with gestalt theory: similarity, continuation, closure, proximity, figure/ground and symmetry & order. These principles were grounded on the natural tendency of humans to find order in disorder (Koffka, 2014; Mann, 2010).

The similarity principle suggests humans tend to group shapes, objects, or design elements that share some similarity in colour, shape, orientation, size, or texture. Similarity ties together items that might not be right next to each other in a design (Koffka, 2014; Mann, 2010), as seen in Figure 1.8.3. In respect of conversations about death and dying, a person may look for similarities or common ground with others who have had similar experiences. This can foster empathy, understanding, and a sense of shared experiences in coping with mortality.

The continuity principle suggests that the human mind prefers to see continuous and smooth paths. It is argued that the objects/shapes positioned in a way that suggests lines, curves or planes will be perceived as such and not as the individual shape/object. Humans will naturally group the elements to form a continuous image (Koffka, 2014; Mann, 2010), as seen in Figure 1.8.3. Concerning death and dying conversations, acknowledging the ongoing impact of an individual's life and legacy after death can provide a sense of continuity.

The closure principle suggests that humans tend to fill in missing information to perceive incomplete figures as a whole. The person's focus automatically fills in the missing parts with similar colours or lines, making the object stable (Koffka, 2014; Mann, 2010), as seen in Figure 1.8.3. Conversations about death and dying can provide closure by dealing with unresolved emotions and expressing final wishes. This can allow the individual to come to terms with the reality of death and dying.

The proximity principle suggests that humans tend to see objects/shapes located near each other as perceived as belonging together (Koffka, 2014; Mann, 2010), as seen in Table 1.8.3. Concerning death and dying, proximity can relate to the conversation of support shared by people facing end-of-life situations. This can bring people closer to each other, creating a sense of togetherness and comfort during difficult times.

The figure/ground principle is when a person can distinguish between the main object of focus (the figure) and the surrounding background (the ground). As seen in Figure 1.8.3, each image relies on the presence of both parts. Only one is the focal figure at a time, whilst the other is the background, highlighting the relationship between the object of focus and its context (Koffka, 2014; Mann, 2010). This principle can be represented in conversations about death and dying as individuals can shift their focus between the immediate details of, for example, the dying process (figure) and the broader context of life, relationships, legacy and memories (ground), and could offer an understanding of the end-of-life experience.

The symmetry and order principle is the tendency to perceive complex or ambiguous stimuli as simple and complete. Our minds naturally seek patterns and organisation in sensory information, which leads us to perceive the most straightforward and coherent form possible. This principle helps to explain how individuals can make sense of the world by organising the visual elements into meaningful and easily understandable patterns (Koffka, 2014; Mann, 2010), as seen in Figure 1.8.3. Within death and dying conversations, the sense of symmetry and order involves organising thoughts, emotions, and practical considerations related to death. This could facilitate clear communication and planning for individuals and their loved ones, especially at the end of life.

Figure 1.8.3

Gestalt principles

Similarity principle	Continuity principle	Closure principle
		
Proximity principle	Figure/ground principle	Symmetry and order principle
		

By using the Gestalt principles in conversations about death and dying, individuals can navigate these discussions with empathy and a sense of understanding, fostering meaningful connections and support.

1.8.4 Coping with death and dying

While death is a taboo subject, there is a wealth of interventions to help individuals cope with death that draw on the theories previously outlined. Support interventions include psychological support groups, counselling, spiritual practices, cultural rituals, and existential approaches (Zhang et al., 2024; De Diego-Cordero et al., 2022; Captari et al., 2023). Therapy sessions support individuals in developing strategies to manage death anxiety effectively while also helping individuals process grief and explore questions (Menzies et al., 2018). Mindfulness exercises, such as meditation and reflective traditions, provide ways to cultivate acceptance and mindfulness in the moment to find peace when faced with mortality (Anālayo et al., 2022). Engaging in creative expression, legacy projects, and end-of-life planning can empower individuals to confront the fear of death, clarify values and leave a meaningful imprint on the world (Sligte et al., 2013; Cui et al., 2020).

Death and dying, for many, are perceived as a reminder that life is finite and valuable (Cozzolino, 2006). The value of life has been reported to be embraced more profoundly by trauma survivors who have been in situations that have led them to contemplate the reality of their death (Tedeschi & Calhoun, 1995; Tedeschi et al., 2018). For some trauma survivors, there is an increased appreciation for life, greater self-reliance and efficacy, heightened compassion, closer connections to people, and a need to prioritise events to find a sense of meaning and, for some, a desire for spiritual development. These individuals often describe that they have a new lease of life, which validates their intrinsic life values/beliefs, such as enlightenment, happiness, and love, and rejects their prior extrinsic values/beliefs, such as money or fame (Tedeschi & Calhoun 1995, Tedeschi et al., 2018).

Research in the field of positive psychology suggests that accepting death can increase resilience, well-being, and psychological growth as people address their existential questions, clarify values, and focus on what holds significance in their lives (Wong & Tomer, 2011, Molamohseni et al., 2024). Philosophers such as the Stoics, who encouraged embracing mortality while building strength and living by the universe's flow, have pondered philosophical viewpoints on embracing death (Inwood, 2018; Sellars, 2020). Stoic teachings on memento mori, known as "remembering death," encouraged people to reflect on their mortality, appreciate life’s nature and embrace the present moment with gratitude and purpose (Inwood, 2018; Sellars, 2020). Existentialist philosophers such as Heidegger and Sartre delved into the concepts of death, freedom, and authenticity, urging individuals to acknowledge the inevitability of death and live courageously and authentically (Heidegger, 2010; Sartre, 2007, 2020).

1.9 Thesis overview

This thesis aims to explore people's lived experiences of their conversations about death and dying, their understandings/experiences of the Death positivity movement, and whether the global pandemic of COVID-19 has influenced their experiences, perceptions, and conversations about death and dying.

Chapter Two details a scoping review of studies exploring death and dying conversations. Forty-seven articles were reviewed, charted, and summarised to identify gaps in the current literature. This chapter also provides the rationale for the current study and a detailed description of the study's aim and objectives.

Chapter Three presents the foundational philosophical influences that have shaped the study. A rationale encompassing an examination of qualitative research paradigms and critically evaluating methodological options within the interpretivist paradigm is given. The chapter delves into the suitability of adopting an interpretive phenomenological approach to address the research aim and objectives, offering insights into phenomenology as both a philosophy and a research methodology and highlighting the contributions of prominent scholars in the field. Additionally, the chapter presents alternative methodological pathways that could have been pursued within the interpretive phenomenological framework.

Chapter Four presents and justifies the methods and their application and reports on how the study was undertaken.

Chapter 5 explores stakeholders' perceptions of conversations about death and dying. One focus group (with four participants) and seven individual interviews were conducted. This resulted in three themes: ‘we are all part of the sea’, ‘shifting death and dying conversations perspectives, and ‘holding hands with death and dying’.

Chapter 6 explores the perceptions of individuals who are living with a life-shortening illness regarding conversations about death and dying. Seven individuals were interviewed, resulting in three themes: ‘death conversation culture: the nature of death and dying conversations’, ‘perceptions about death and dying: influences on death and dying conversations’, and ‘readiness to engage in death and dying conversations’.

Chapter 7 explores the perceptions of individuals who are not living with a life-shortening illness regarding conversations about death and dying. Seven individuals were interviewed, resulting in three themes: ‘the nature of death and dying conversations’, ‘perceptions about death and dying: influences on death and dying conversations’, and ‘readiness to engage in death and dying conversations’.

Chapter 8 offers the discussion, limitations, future research and concluding message.

1.10 Summary

This chapter elucidates my interest in the psychology of death and dying and the rationale for focusing my thesis on death and dying conversations. It presents a nuanced overview of death and dying, encompassing historical and contemporary perspectives, and discusses taboos, fears, and acceptance of mortality from diverse viewpoints and cultural perspectives.

Every culture has unique customs, beliefs and practices related to death that shape individuals' attitudes toward mortality. In Western societies, death is often considered a subject to be avoided and denied, resulting in social taboos around discussing it openly. Religious beliefs and spiritual rituals provide frameworks for coming to terms with our fear of dying.

Accepting death is a 'journey' that prompts individuals to face their mortality with bravery, wisdom, and compassion. By exploring the psychological, philosophical, cultural, and spiritual dimensions of death acceptance, valuable insights can be gained into the transformative power of embracing mortality as an integral aspect of life. Accepting death can promote resilience, meaning, and connection in the face of uncertainty and help us understand the impermanence of life as a sacred and profound part of the human experience.

The chapter briefly considered how living with a life-shortening condition, the assisted dying/euthanasia movement, living in a digital age, and the COVID-19 pandemic each have an impact on perceptions of death and dying and related universal conversations. The emergence of the death-positive movement, advocating for openness towards death and dying, alongside reflections on the evolving societal attitudes towards death and dying, is discussed. Furthermore, theories relevant to the psychology of death and dying are outlined as they offer an understanding of the phenomena of interest and provide insights into how people cope with their death and dying-related experiences and perceptions. Finally, the chapter outlined the focus of the thesis, detailing the content of subsequent chapters.

Chapter 2

A scoping review of the literature

"It is not death that a man should fear, but he should fear never beginning to live."
Marcus Aurelius

2.1 Introduction

This chapter will explore the literature relating to conversations about death and dying. The scoping review's purpose was to map the current evidence and identify gaps in the literature before embarking on an empirical study. The aim of the scoping review, methods, procedures, findings, and discussion are presented. The limitations of the review will also be considered in relation to the findings. The review's key findings will be contextualised by linking to the theoretical perspectives highlighted in Chapter One.

2.2 Review context

A literature review aims to answer a specific question, present and summarise available evidence on a topic, highlight gaps in the evidence and areas for future research and potentially shape policy. Reviews typically offer a critical evaluation of research, identify patterns and discrepancies in the literature, aid in constructing theoretical frameworks or research hypotheses/questions, and place the research into wider academic and clinical conversations (Noble & Smith, 2018).

Grant & Booth (2009) identified 14 different types of reviews, broadly divided into four groups: systematic reviews, narrative (or descriptive) reviews, meta-analysis reviews, and scoping reviews. Systematic reviews are well-known for their rigorous methodology. They follow a detailed protocol and processes that systematically undertake a comprehensive and reproducible search to identify relevant studies and, where possible, synthesise and critically analyse the included study findings. This methodical approach reduces bias and ensures objectivity, making systematic reviews rigorous, reliable and unbiased. Consequently, they are deemed the highest quality in evidence-based research, offering a precise and thorough evaluation of the existing evidence to answer a particular and specific research question (Centre for Reviews and Dissemination (CRD), 2009). While systematic reviews are considered the gold standard and the best method for a thorough literature evaluation, there may be more suitable choices depending on the question, study designs, and complexity of the topic area.

Narrative reviews offer a structured chronicle of the literature to produce a coherent story, delivering a thorough summary of a particular subject. Within these reviews, there is usually a historical background and broad awareness of the explored topic. This type of review can benefit researchers seeking to build a fundamental grasp of the range of research undertaken in the area of focus. This type of review is valuable when historical context or a broad overview is essential for understanding the present knowledge status in a field (Sukhera, 2022). However, narrative reviews have been criticised for lack of reproducibility, and often, the search is limited because of a lack of resources (Noble & Smith, 2018).

A meta-analysis review combines studies to enhance the credibility of findings offered by an individual study. Statistically, meta-analysis reviews are particularly beneficial for assessing the effect size or significance of a specific intervention, treatment, or phenomenon (Gurevitch et al., 2018). However, a lack of homogeneity between studies, data collected, and analytic methods can render the statistical combining of results meaningless, resulting in bias.

Scoping reviews aim to chart the current literature landscape, pinpointing areas that need further exploration and refining research inquiries. These reviews can offer a broad perspective of existing research and are especially beneficial when researchers initiate exploratory investigations or aim to grasp the full scope of a subject before undertaking a focused research study (Peters et al., 2021). The rationale for choosing a scoping review and its advantages and disadvantages are outlined below.

2.2.1 Scoping review

A scoping review was considered the most appropriate strategy for this review to map the existing literature in a broad context - which is pertinent as the topic has not been comprehensively reviewed previously, allowing for the identification of a range of evidence (Arksey & O’Malley, 2005; Rodger, 2024). Furthermore, this review style enables a broad overview of context and settings, populations and research approaches undertaken about death and dying conversions. Unlike systematic reviews, which focus on answering specific research questions, a scoping review is broader in scope and can often be used to explore emerging areas of research or to identify gaps, strengths, and weaknesses in the existing literature (Colquhoun et al., 2014; Rodger, 2024). A scoping review will provide an overview of the available evidence and identify key concepts and types of evidence regarding the conversations of death and dying. Scoping reviews, like systematic reviews, systematically search multiple databases and other sources to identify relevant studies. The inclusion criteria, however, are often broader compared to systematic reviews, allowing for a more comprehensive overview of the topic.

Data is extracted and summarised after identifying relevant studies and findings presented descriptively, highlighting key themes, trends, and gaps. As with systematic reviews, the comprehensive search strategy includes searching for ‘grey’ literature (Manietta et al., 2022). Grey literature can provide valuable information and research findings that are not readily available through regular research databases and can offer insights, data and perspectives that complement or expand on current published literature. Though grey literature may lack the rigorous peer-reviewed process generally associated with scholarly publications, it can still highlight credible and valuable information and future research directions (Manietta et al., 2022). Unlike systematic reviews, typically, scoping reviews do not undertake an in-depth analysis of the findings or attempt to combine findings such as a quantitative or qualitative meta-synthesis.

2.3 Aim and objectives

The review aimed to map the evidence about death and dying conversations in Western societies. The specific objectives were to:

(1) identify studies that have explored people’s experiences of death and dying-related conversations across the lifespan within contemporary Western society;
(2) describe what conversations of death and dying occur and in what contexts and settings;
(3) describe how death and dying conversations occur in settings outside of palliative/clinical care at end-of-life and related psychotherapeutic contexts.

2.4 Methods

This section will discuss the methods used, search protocol, sampling methods, selection criteria and search strategy.

2.4.1 Review framework

A review protocol was developed using the Preferred Reporting Items for Systematic Reviews and Meta-analysis Scoping Reviews (PRISMA-ScR) as outlined in the Joanna Briggs Institute Reviewer’s Manual of Reviews (Tricco et al., 2018). The PRISMA-ScR framework was developed from Arksey & O’Malley’s (2005) original framework for conducting scoping reviews. Levac et al. (2010) extended the framework further, labelled a ‘systematic scoping review’ framework, adding a clear structure to the review methods, and finally, Peters et al. (2015, 2017) developed and refined the framework to the PRISMA-ScR. Applying the PRISMA-ScR framework allowed for this scoping review to be rigorously conducted. The adapted framework is illustrated in Table 2.4.1 and was used to guide this review.

Table 2.4.1

Integration of scoping review frameworks

Item	Arskey & O'Malley framework (2005, p. 22-23)	Enhancements proposed by Levac et al., (2010, p. 4-8)	Enhancements proposed by Peters et al., (2015, 2017, 2020)
1	Identifying the research question /aim	Clarifying and linking the purpose and research question	Defining and aligning the objective/s and question/s
2	Identifying relevant studies	Balancing feasibility with breadth and comprehensiveness of the scoping process	Developing and aligning the inclusion criteria with the objective/s and question/s
3	Study selection	Using an iterative team approach to selecting studies and extracting data	Describing the planned approach to evidence searching, selection, data extraction, and presentation of the evidence
4	Charting the data	Incorporating a numerical summary and qualitative thematic analysis	Searching for the evidence
5	Collating, summarising and reporting the results	Identifying the implications of the study findings for policy, practice or research	Selecting the evidence
6	Consultation (optional)	Adopting consultation as a required component of scoping study methodology	Extracting the evidence
7			Analysis of the evidence
8			Presentation of the results
9			Summarising the evidence in relation to the purpose of the review, making conclusions and noting any implications of the findings

The first stage of a literature review is to identify and develop a well-defined purpose for the review. Chapter 1 presented the background to this review, where concepts associated with death and dying were considered, including different worldviews, contexts, and theoretical perspectives. The aims and objectives presented in Section 2.3 were developed from Chapter 1 and discussions in supervisory meetings.

2.4.2 Identifying relevant studies: sampling methods

Two frameworks were considered when developing the sampling methods, the most accepted of which is the PICO framework (Population, Intervention, Comparison, Outcome). At the same time, the widely adopted PICO framework has limitations, mainly if the review is focused on something other than healthcare intervention (Hosseini, 2024). A more appropriate framework for exploring research on conversations about death and dying, and more tailored for qualitative research, which was adopted, is PICo, a variation of the PICO. PICo refers to:

P: Population - describes the participants or group, which for this review is people across the lifespan.

I: Interest - specifies the phenomenon or main concept being explored, and for this review, the topics are the conversations regarding death and dying, meaning-making and decisions regarding death and dying.

Co: Context - identifies the broader context or setting where the study occurs. This review includes all clinical, non-clinical, or social settings. All research design types include qualitative, quantitative, mixed methods, narrative, etc.

2.4.2.1 Selection criteria

The selection criteria for this review were broad to capture all study designs that might have been adopted to explore people's conversations about death and dying. Table 2.4.2.1 outlines the inclusion and exclusion criteria.

Table 2.4.2.1

Inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
• All age groups • Conversations about death and dying, death and dying meaning-making • Decisions about death and dying • Clinical, non-clinical and social settings • Qualitative, quantitative, and mixed methods research. • Biopsychosocial and spiritual contexts. • No date restrictions.	• Theoretical perspective. • Legal positions. • Studies that primarily focus on professional burnout, criminology, diagnosed mental health conditions • Studies that centre on the development and evaluation of standard psychotherapeutic interventions. • Clinical care at the end-of-life.

2.4.2.2 Sampling strategies

A range of health and social care databases were searched: PsycINFO (Ovid, Proquest interface) (1806-2022), which indexes articles in psychology and related fields; CINHAL (EBSCO Interface) (1981-2022), available through the EBSCO interface, is a specialised nursing and allied health literature database and includes a wide range of journals and a depth of health-related topics, in nursing, health sciences, and related fields. In addition, Web of Science was searched because it is a multidisciplinary citation database that covers a wide range of academic disciplines and includes scholarly articles, conference proceedings, and other academic resources. The databases searched intended to provide a comprehensive search of related topics and study designs about people's conversations about death and dying. The initial search was conducted in 2020, with further updated searches conducted in 2022 and 2024 to capture later studies. The search terms, which were adapted for each database, were:

1. Death or dying or deceased or die
   AND
2. Communication or discussion or conversation or dialogue or talk
   AND
3. Perception or perspectives or situation
   AND
4. Intervention or measures or decision-making or meaning-making or support.

Whilst database search engines are advanced, some pertinent articles may not be captured due to how the keywords are indexed. For instance, articles with ambiguous titles may not be appropriately indexed.

2.5 Procedures

This section will discuss the procedures for selecting included studies and data extraction. A scoping review maps the existing literature on a broad topic to identify key concepts, sources, and gaps in research.

2.5.1 Selection of articles

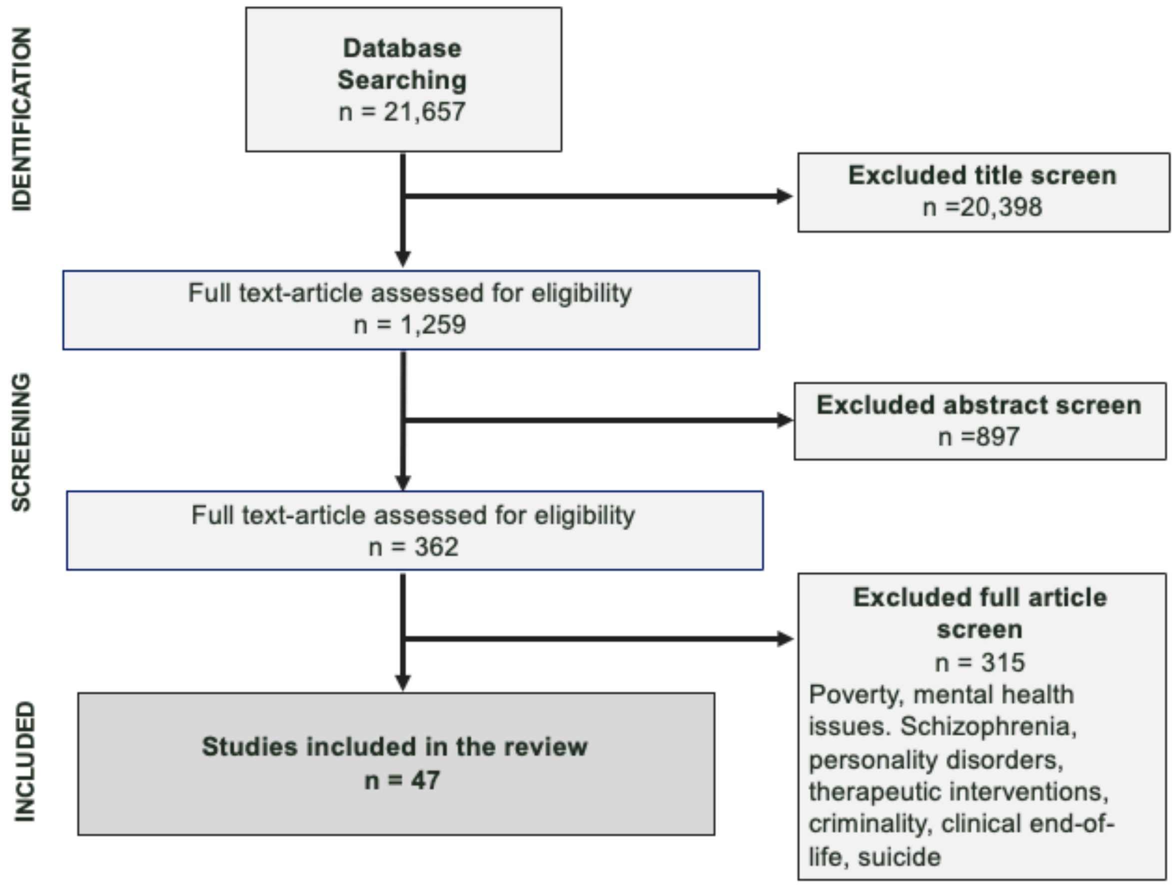
Phase 1: the search returned 21,657 articles. The article titles were read, and any that did not meet the search criteria were removed, reducing the number of articles for further review to 1,259. Attempts were made to search the grey literature, using the same search parameters to find unpublished work, websites, and reports. Grey literature can be sourced from blogs, emails, tweets, books, magazines, reports, and news articles (Adams et al., 2017) and reports from public, private and non-profit organisations (Booth et al., 2016). However, this returned a vast number of items and was mainly anecdotal. A decision was made to use only research found within the databases noted above.

Phase 2: the abstracts of the articles after title screening were read and again excluded if they did not meet the selection criteria. The main reasons for exclusion were a focus on poverty issues, mental health issues, suicidal thoughts/behaviours, schizophrenia, personality disorders, criminality, mortality salience manipulations, dreams, and book reviews. In the second screening, 47 were identified as related to discussions about death and dying, and after a final evaluation, all met the inclusion criteria. Figure 2.5.1 presents a PRISMA flow diagram of the screening process, including reasons articles were rejected.

Phase 3: in-depth reading of the 47 articles involving a comprehensive evaluation of each article’s methods, results, discussion, implications, and data charting (Section 2.5.3). Additionally, gaps in the existing literature, proposed future research directions, and the broader implications of the findings on theory, practice, and policy were noted.

Figure 2.5.1

Study selection process



2.5.2 Charting the data

Charting the data for this scoping review was an iterative process involving organising and summarising each article and creating a table summarising key information, such as study aims, methods and key findings. As Levac et al. (2010) suggested, charting should include numerical and narrative summaries of key findings and be presented throughout the findings below. To ensure consistency when extracting data, a form was created to chart information about each study reviewed and to aid decisions about whether to include or exclude (see Appendix 1).

2.5.3 Overview of included studies

Forty-seven articles met the review aim, objectives, and selection criteria and were included in the review. Appendix 2 provides a summary table of included studies detailing study characteristics, such as geographic location, title, aims, methods, and key findings.

2.5.3.1 Geographic locations

The studies included in the review were undertaken in Western societies such as North America, Canada, the UK, and Australia. For a full tabulated breakdown of the geographical locations, refer to Appendix 3.

2.5.3.2 Participant characteristics

Study participants were grouped into three groups: those who did not have a life-shortening illness, those with a life-shortening illness, and others who included educational settings (clinical and non-clinical). See Appendix 3 for tabulated participant characteristics.

2.5.3.3 Living without a life-shortening illness

Approximately a quarter of studies (11 of the 47 studies) included participants 18 to 88 years old who did not have a life-shortening illness and focused on understanding the Death Café spread across the world (Richards et al., 2020); training programmes (Schiltz et al., 2014; Tieman et al., 2018); healthy older adults talking about future life planning (South & Elton, 2017; Taylor, 2021; Llewellyn et al., 2017; Malcomson & Bisbee, 2009;); reflecting on death (Takeuchi et al., 2021); interventions (von Blanckenburg et al., 2020); end-of-life communication (Oosterveld-vlug et al., 2016; Cherlin et al., 2005)

2.5.3.4 Living with a life-shortening illness

Five studies researched parents' perspectives of conversations about death and dying when faced with their children’s life-shortening illnesses (Su-Russell et al., 2021; Kennedy & Williams, 2009; Kars et al., 2015; Bartels & Faber-Langendoen, 2001; Van der Geest et al., 2015). Nine studies provided a unique perspective on coping with a life-shortening illness (Applebaum & Applebaum, 2019; Walczak et al., 2013; Wiener et al., 2008; Willig, 2015; Piers et al., 2013; Cassano et al., 2008 Coyle, 2006; Au et al., 2012; Chiu et al., 2012). One study focused on veterans who were coping with lower extremity amputations that could lead to death due to the complications of peripheral arterial disease and diabetes (Henderson et al., 2023). Two studies explored the perspective of those with life-threatening conditions in remission (Robinson et al., 2015; Keim-Malpass, 2012).

2.5.3.5 Educational settings (clinical and non-clinical)

Six studies included health professionals from hospitals, care staff and nurses (Hales & Hawryluck, 2008; Clarke & Ross, 2006; Au et al., 2012; Nedjat-Hacem et al., 2016; Osterlind et al., 2011; Johnson & Bott, 2016).

Six studies involved students, students ranging from school-age to college/university-age and medical students (Ellison & Radecke, 2005; Thornton, 1991; Üzar-Özçetin et al., 2020; Bloomfield et al., 2015; William-Reade et al., 2018; Nellis et al., 2016). One study used educational tools with patients who were living with cancer (Li et al., 2023). Two studies explored the conversations between residents of a care home and medical staff (Schaffer et al., 2012) and nursing care patients and their families (Gjerberg et al., 2015).

2.5.3.6 Clinical settings

Most studies (30 of 47) were undertaken in clinical settings. Refer to Appendix 2 and 3 for tabulated clinical settings study information. Non-clinical settings included studies undertaken by Richards et al. (2020); South & Elton (2017); Waldrop et al. (2004); Applebaum & Applebaum (2019); Schiltz et al. (2014); Margola et al. (2010); Zajac & Boyatzis (2020); Robinson et al. (2015); Ellison & Radecke (2005); Thornton (1991); Tieman et al. (2018); Su-Russell et al. (2021); Taylor (2021); Takeuchi et al. (2021); Llewellyn et al. (2017); Keim-Malpass (2012); Chiu et al. (2012).

2.5.3.7 Study designs/methods

The majority (29 of 47) study designs were qualitative, which was anticipated as qualitative approaches aim to understand the individuals' lived experiences, perspectives, and social phenomena in-depth to uncover meanings and patterns to generate insights rather than numerical data. Only five of the 47 articles detailed the sampling method used (South & Elton, 2017; Nedjat-Haiem et al., 2016; Au et al., 2012; Cassano et al., 2008; Üzar-Özçetin et al., 2020). Refer to Appendix 3 for Tabulated methods information. Methodologies for the studies review were mainly descriptive, phenomenological, and grounded theory.

2.5.3.8 Data collection methods

The studies included a range of methods to collect data, such as surveys, interviews, open-ended questionnaires, and experiments in keeping with qualitative research methods (Moser & Korstjens, 2018). Twenty-three studies used surveys, including questionnaires (Waldrop et al., 2004; Schiltz et al., 2014; Ellison & Radecke, 2005; Tieman et al., 2018; Hales & Hawryluck, 2008; Bloomfield et al., 2015; William-Reade et al., 2018; Cherlin et al., 2005), survey measures (Taylor, 2021; Takeuchi et al., 2021; Von Blanckenburg et al., 2020; Su-Russell et al., 2021; Johnson & Bott, 2016; Silverman & Worden, 1992; Au et al., 2012; Li et al., 2023), self-reporting questionnaires (Margola et al., 2010; Nellis et al., 2016;), and open-ended questionnaires (Zajac & Boyatzis, 2020; Su-Russell et al., 2021; William-Reade et al., 2018; Van der Geest et al., 2015), and one used a vignette (Su-Russell et al., 2021). Twenty of included studies used interviews as their data collection method (Richards et al., 2020; Applebaum & Applebaum, 2019; Robinson et al., 2015; Taylor, 2021; Llewellyn et al., 2017; Walczak et al., 2013; Gjerberg et al., 2015; Kennedy & Williams, 2009; Wiener et al., 2008; Willig, 2015; Kars et al., 2015; Bartels & Faber-Langendoen, 2001; Silverman & Worden, 1992; Cherlin et al., 2005; Piers et al., 2013; Cassano et al., 2008; Coyle, 2006; Nedjat- Haiem et al., 2016; Li et al., 2023 Henderson et al., 2023). There were eleven focus groups, one of which was described as a discussion group (South & Elton, 2017; Thornton, 1991; Schaffer et al., 2012; Walczak et al., 2013; Gjerberg et al., 2015; Osterlind et al., 2011; Clarke & Ross, 2006; Bloomfield et al., 2015; Malcomson & Bisbee, 2009; Oosterveld-vlug et al., 2016; Chiu et al., 2012). Two studies collected data from online blogs (Keim-Malpass, 2012; Üzar-Özçetin et al., 2020), and one used recordings from a more extensive study (Bartlet et al., 2022). Interviews and focus groups were the most used methods. These methods provide flexibility, allowing participants to share their lived experiences from their conversations about death and dying. Refer to Appendix 3 for Tabulated details on data collection methods.

2.5.3.9 Data analysis methods

In keeping with study designs, qualitative methods primarily underpinned data analysis. Ten studies undertook thematic analysis (Richards et al., 2020; Zajac & Boyatzis, 2020; Robinson et al., 2015; Taylor, 2021; Walczak et al., 2013; Bloomfield et al., 2015; Bartels & Faber-Langendoen, 2001; Nellis et al., 2016; Oosterveld-vlug et al., 2016; Nedjat- Haiem et al., 2016). Five studies used qualitative content analysis (Schiltz et al., 2014; Malcomson & Bisbee, 2009; Bartlet et al., 2022; Henderson et al.,2023). Three studies adopted grounded theory (South & Elton, 2017; Kennedy & Williams, 2009; Kars et al., 2015). One study alluded to using grounded theory, describing open, axial and selective coding, but needed to be more explicit (Li et al., 2023). Four undertook constant comparative analysis, an analytic method derived from grounded theory (Su-Russell et al., 2021; Clarke & Ross, 2006; Cassano et al., 2008; Cherlin et al., 2005). One adopted narrative analysis (Applebaum & Applebaum, 2019). Three adopted an adaptation of hermeneutic and interpretive phenomenology (Keim-Malpass, 2012); Ethnography guided by hermeneutic phenomenology (Willig, 2015; Coyle, 2006). One undertook discourse analysis (Osterlind et al., 2011). Two adopted framework analyses (Van der Geest et al., 2015; Piers et al., 2013). Four studies did not report the method of data analysis within their method section but produced a narrative of participants' evaluations (Waldrop et al., 2004; Ellison & Radecke, 2005; Thornton, 1991; William-Reade et al., 2018). Five studies used other analysis methods such as qualitative systematic text condensation (Üzar-Özçetin et al., 2020); analytic approach of immersion/crystallisations (Llewellyn et al., 2017); Hamilton's contractual/community model (Schaffer et al., 2012); Bricolage (Gjerberg et al., 2015); ground approach analysis (Chiu et al., 2012); textual analysis (Margola et al., 2010).

Sixteen studies of the quantitative undertook a range of statistical analysis methods such as t-tests, MANOVA, ANOVA, and correlations (Schiltz et al., 2014; Margola et al., 2010; Tieman et al., 2018; Su-Russell et al., 2021; Taylor, 2021; Takeuchi et al., 2021; Hales & Hawryluck, 2008; Von Blanckenburg et al., 2020; Bloomfield et al., 2015; Wiener et al., 2008; Nellis et al., 2016; Silverman & Worden, 1992; Cherlin et al., 2005; Oosterveld-vlug et al., 2016; Johnson & Bott, 2016; Au et al., 2012).

Nine studies included both qualitative and quantitative analysis methods using primarily descriptive statistics, t-tests, and thematic analysis (Schiltz et al., 2014; Margola et al., 2010; Su-Russell et al., 2021; Taylor, 2021; Bloomfield et al., 2015; William-Reade et al., 2018; Cherlin et al., 2005; Li et al., 2023; Silverman & Worden, 1992). Refer to Appendix 3 for Tabulated details on data analysis methods.

In summary:

- Forty-seven articles met the review aim, with most studies undertaken in healthcare settings. Few studies explore the wider society’s views of death conversations.
- Participants were wide-ranging, including doctors, nurses, care assistants, patients, family, children and students.
- Approximately two-thirds of studies were qualitative designs, mainly adopting the two most common methodological approaches of grounded theory and phenomenology.
- Data collection was done in keeping with qualitative approaches, primarily interviewing and the relevant qualitative data analysis.

Details of study characteristics, including methodologies and methods undertaken, are presented in Appendix 2.

2.6 Collating, summarising and reporting the results

This review aimed to map the literature that has addressed people's conversations about death and dying, detailing the contexts and settings in which these conversations occurred both inside and outside of a clinical setting. Therefore, the articles reviewed were grouped based on the review objectives.

2.6.1 Objective 1: Studies that have explored people’s experiences of death and dying-related communications across the lifespan within contemporary Western society

The review methods identified 47 studies about conversations or communication about death and dying, with 32 studies focusing on palliative care, end-of-life care, or end-of-life discussions. While not explicitly focusing on conversations about death and dying, one study was included because it explored writing aids for dealing with the trauma of the impact of a sudden death, and the findings had relevance (Margola et al., 2010). Findings from this study highlighted that writing their thoughts and feelings about the death helped deal with their emotions about a traumatic and life-threatening event.

2.6.1.1 The value of writing about death and dying

Writing can enable individuals to explore their emotions before reflecting on and understanding them. As seen in Margola et al., (2010). This mixed methods study of 20 students who experienced the sudden death of a classmate included baseline measures 14 days after the death, where students wrote about their emotions for three consecutive days, then repeated the activity again at one week and four months post-writing. Writing was found to help with the process of cognitive and emotional processing of the trauma. Another form of writing is storytelling; individuals can foster connection, empathy, and support with others navigating the complexities of mortality, as reported in two of the articles reviewed. For example, in the study by Chiu et al. (2012), participants wrote blogs about their lives. They could express their emotions and find comfort in reading other blogs written by people with the same illness which allowed them to create a legacy for their family to remember them.

Similarly, in a study undertaken by Keim-Malpass (2012), female participants also used online blogs (aged between 20-39, diagnosed with cancer). They shared how they could express their emotions, exchange information and receive support through blogging. The process was cathartic for these young women to express their feelings to others who understood their situation. Though these studies did not explicitly relate to conversations about death and dying, writing about death and dying facilitates the expression of emotions in a similar way to conversations.

2.6.1.2 The age and background of participants

There was a diverse age range of participants across studies reviewed and across the lifespan, including children who had lost a parent (Kennedy & Williams, 2009), adolescents with a life-shortening illness (Cassano et al., 2008; Wiener et al., 2008), adults living with a life-shortening illness (Coyle, 2006 Chiu et al., 2012 Willig, 2015), and older adults discussing advanced care planning (Piers et al., 2013. Malcomson & Bisbee, 2009). However, only one study with children involved a focused discussion about children's perceptions of death and dying and was in the context of organ donation (Waldrop et al., 2004). The other studies involving children were connected to bereavement or support groups (Margola et al., 2010; Cassano et al., 2008; Kennedy & Williams, 2009).

Participants included parents who struggled to understand their dying child's perspective (Kars et al., 2015); communications between medical staff and families (Bartels & Faber-Langendoen, 2001); healthcare professionals from a range of professional backgrounds, including doctors, nurses and healthcare assistants (Nellis et al., 2016 Johnson & Bott, 2016 Nedjat-Haiem et al., 2016 William-Reade et al., 2018); individuals who had experienced the death of a fellow adolescent peer (Margola et al., 2010).

2.6.1.3 Religion, spirituality, faith and culture

Religion, spirituality, faith and culture were not prevalent in this review. There was only one study that discussed religion; Zajac & Boyatzis (2020) found that the parent's religious and spiritual views shaped the conversations and influenced their decision and perceived a benefit to having conversations about death and dying with their children.

2.6.1.4 Education

Educational programs were evaluated in 9 studies that developed or evaluated age-appropriate information and guidance on end-of-life care (Hales & Hawryluck, 2008; Au et al., 2012; Ellison & Radecke, 2005; Thornton, 1991; Bloomfield et al., 2015; William-Reade et al., 2018; Nellis et al., 2016; Schiltz et al., 2014; Llewellyn et al., 2017). Education as a tool was found to prepare students to discuss death, but they found that age maturity was a factor in how participants engaged with the information. Similarly, Ellison & Radecke (2005) found that the students aged between 13-18 who attended the course had a positive outcome about death and dying. However, they also noted that four participants would not recommend the course or attend again. Overall, the positive effect of education was found in studies that included older adults, who typically have a more nuanced understanding of death's permanence. For example, Schiltz et al. (2014) found positive feedback from attending a death and dying course. Participants developed a deeper understanding of death and dying, had more of an open mind towards the topic, and could understand different viewpoints of life after death. Additionally, Llewellyn et al.’s (2017) study of people 54-65 years of age suggested that engagement with structured conversations about death and dying allowed them to have a more meaningful exploration of their psychosocial, spiritual and cultural contexts.

2.6.1.5 Setting/context

The 27 articles included that focused on a clinical setting such as hospitals or care homes had a range of aims, for example, health professionals’ perceptions of death and dying (Schaffer et al., 2012; Osterlind et al., 2011; Clarke & Ross, 2006; Nedjat-Haiem et al., 2016), educational needs (Bloomfield et al., 2015; Williams-Reade et al., 2018), advanced care planning and experiences with dealing with death and dying (Piers et al., 2013; Malcomson et al., 2009); individuals with a life-shortening condition and their perceptions and lived experiences (Willig, 2015; Kein-Malpass, 2012); palliative care/end-of-life or have faced some form of bereavement within their lives (Kars et al., 2015; Bartels et al., 2001; Van der geest et al., 2015). However, across the studies, a common thread related to narratives around the loss of a family member and discussing/writing about death and dying appeared to help individuals deal with their situation. This commonality allowed the participants to share their views on death and dying more openly with others in similar situations. Outcomes following these shared stories/reflections include greater empathy and modifying dysfunctional thoughts (Keim-Malpass, 2012; Yu-Chen et al., 2012; Robinson et al., 2015; Willig, 2015; Cassano et al., 2008; South & Elton, 2017; Kennedy & Williams, 2009). For health professionals, in particular, there was an increased level of confidence to communicate with individuals facing their imminent death; for some, their confidence levels related to an increased open-mindedness around death and dying (William-Reade et al., 2018; Bloomfield et al., 2015; Hales & Hawryluck, 2008).

2.6.3 Objective 2: What conversations of death and dying occur, and in what contexts and settings?

Death and dying conversations were explored across populations and in different contexts. Most studies focused on patients receiving palliative/clinical end-of-life care in specific clinical settings such as primary care, for example, Hales & Hawryluck (2008), Üzar-Özçetin et al. (2020), Walczak et al. (2013), Osterlind et al. (2011), Clarke and Ross (2006), Wiener et al. (2008), Bartels & Faber-Langendoen Bartlet et al. (2022), and Nedjat- Haiem et al. (2016); or care homes, for example, Schaffer et al. (2012), Gjerberg et al. (2015), Nellis et al.(2016), and Johnson and Bott (2016). Several studies were undertaken in educational settings, such as Tieman et al. (2018), Schlitz et al. (2014), Ellison and Radexke (2005), Thornton (1991), Bloomfield et al. (2015) and William-Reade et al. (2018) and Waldrop et al., (2004). One study explored the stories of individuals and the time they experienced with a dying person (Applebaum & Applebaum, 2019). The study presented a narrative between a son and a father. Here, the participant was a surgeon diagnosed with cancer, and the father of the researcher reported a snapshot of their discussions; it was not a therapeutic encounter but a son sharing his thoughts with his father as his father's illness progressed. These conversations allowed discussions about their fears, losses openly, and missed opportunities. An extract shows how the son used his work as a coping mechanism.

"*Your diagnosis was tough on me. As a pediatric oncologist, I knew metastatic anything was bad in adults. Since then, I have worried about how you would handle being a cancer patient. I also worried about my mom a child psychiatrist, whose own defense mechanism was to try to psycho analyze you. Not knowing how else to support you and Mom from a distance, I fell back onto what I know how to do well, I looked up the latest research and contacted every prostate expert I could to see what treatments made the most sense*".

Documenting their thoughts and conversations allowed other family members to access them, read the stories, and appreciate the insights of the son and father's experiences. Though this study reports a summarised version of the conversations, there is a suggestion that the father could talk about his thoughts of death and dying and related perceptions and stories, which he had not been able to discuss before his illness, as seen by what the son wrote at the end of the article.

"Upon reading our story, my mother and sister were both amazed that the thoughts and stories my dad put into this piece are more than he's shared with anybody about his entire cancer

journey, and it was fascinating for all of us to learn about my grandfather's take on antibiotics. This process has helped me appreciate how much my dad is a product of his surgical training."

By talking openly and receiving the family's response, it could be inferred that having conversations regarding death and dying could have positive benefits.

2.6.3.1 Space to talk

Safe spaces can also allow for open conversations about death and dying. For example, Masters et al. (2023) brought together a cohort of undergraduate students paired with older people to discuss death and dying. The participants revealed that talking to someone from a different generation about death and dying was meaningful. In addition, both groups expressed that engaging in conversations about life, death and dying during the pandemic prompted introspection on their mortality, values and connections. The researchers also suggested that online conversations allowed people to be more open and self-disclose.

Within this scoping review, some studies about death and dying-related interactions collected data using web blogs, reporting findings on how conversations about death and dying can take different forms and be experienced using other media. For example, Keim-Malpass (2012) investigated the perspectives of young women who had cancer and their use of online blogs as a medium to share their feelings. It was found that the participants could express their emotions freely via the online platforms and that their blogging and responding were cathartic. The study findings suggest that when there are perceived safe spaces, people are more able to talk freely and openly about death and dying. The researchers postulated a dichotomy between online and offline spaces within contemporary Western society. Some individuals may be more open and prepared to have online conversations regarding death and dying, yet others may prefer face-to-face openness. This finding suggests who the discussions are with, and their purpose influences the choice of communication medium.

2.6.3.2 Relationships matter

Death and dying can prompt the individual to re-evaluate priorities, deepen connections and foster a greater appreciation for their loved ones. One study focused on relationships and investigated how religion is involved in discussions about death and dying (Zajac and Boyatzis, 2020). The researchers asked questions of mothers with children between the ages of 8-14 and found that talking about death was beneficial to children in emotional, social, and intellectual ways. Improvements in conversations between parents and children developed as the bonds between them became stronger following having had conversations about death and dying.

2.6.4 Objective 3: How death and dying conversations occur in settings outside of palliative/clinical care at end-of-life and formal psychotherapeutic contexts.

2.6.4.1 Non-clinical settings

Seventeen studies explored death and dying outside of palliative/clinical care and end-of-life care contexts, such as those examining online blogs (Chiu et al., 2012). Chiu's study explored online blogs of people with a life-shortening illness and found that individuals could reconstruct their life stories through blogging. In addition, by reading other people's blogs, people could make sense of their prognosis and had a more significant influence than a doctor. The blog also left a legacy for family members to be able to remember them after they had died.

One study explored informal death conversations with data collected by research assistants transcribing the friends and family discussing death and dying over the dinner table (South & Elton, 2017). Findings suggested friendship groups were more candid with their conversations than family groups. However, the researchers found several contradictions in participants' accounts, for example:

1) A perception that family members would be able to share possessions as directed but may not follow their end-of-life wishes.

2) A belief in wills and advanced directives yet felt no need to plan them in the near future.

3) Not wanting themselves or loved ones to die in hospital, but a lack of trust in hospice or palliative care. There appeared to be a misunderstanding of what hospice/palliative care/end-of-life care meant.

4) A perception that the organ donation process was untrustworthy.

This study was undertaken in America, which has a different organ donation process to the UK. However, in addition to the contradictions, a key finding was that most participants came away from the experience with a positive perspective of death and dying conversations. The contradictions appear to be misunderstandings of processes or how specific guidance operates in practice, inferring that there is a need to have accurate information regarding the death and dying process.

Chiu et al., 2012, and South & Elton, 2017 make compelling arguments for safe, relaxed, and comfortable settings to facilitate open and frank discussions. If individuals have a space where they feel they can be more open to discussing death and dying, it could help alleviate some fears surrounding death and dying.

2.6.4.2 Educational settings

Evidence suggests that providing death education to children and adults can facilitate conversations about death and dying. A study by Tieman et al. (2018) explored adult participants' views of death and dying and their attitudes towards it after participating in an online learning course. The researchers found that online learning provided a safe space for participants to explore their feelings and perspectives on death and dying. Those who had initial difficulty with the subject reported being more comfortable by the end of the course. This research suggests a transition or developmental process is experienced to become accepting of death and dying conversations. This notion is supported further by Schlitz et al. (2014), Ellison & Radexke (2005), and Thornton (1991), whose participants undertook courses about death and dying, all with positive outcomes. For example, participants reported gaining a deeper understanding of their mortality and broader perceptions of death and dying.

Several studies within this review explored health professionals' education, such as Bloomfield et al. (2015) and William-Reade et al. (2018). Bloomfield et al. (2015) aim to enhance students' understanding of the importance of open communication during end-of-life care conversations. Nineteen medical students participated in the focus group, and 27 participated in the simulated teaching sessions involving actors as patients in real-world situations. The researchers found a significant increase in competence and confidence about engaging in death and dying conversations among the students after participating in the simulated scenarios. Similarly, Williams-Reade et al. (2018) also explored communication skills for surgical residents when breaking bad news. Students undertook two 30-minute simulations and found increased confidence and skills in communicating difficult information to families after the simulated sessions. Students also rated the sessions as extremely useful and realistic, and from follow-up surveys, they retained the skills learnt and changed practices when dealing with patients and families. These studies suggest that education can improve communication and prepare students to engage meaningfully with dying patients and their families.

One study explored the perceptions of organ donation among school children aged 11-18 (Waldrop et al., 2004). The school children participated in a thirty-minute presentation about the need for organs and information about organ donation, using stories from recipients and donor family members. Following the presentation, there was a question-and-answer session, and the children were given a guide to help them initiate and facilitate conversations about organ donation with their families. The researchers postulated that participating in the research would prepare children to start discussions outside the educational setting. However, there was a difference between the school children being informationally prepared and emotionally ready to lead this conversation. The children reported being anxious about initiating family conversations about organ donation, which the researchers suggested may be due to the age and maturity of the students. The researchers also noted that very few of the families and school children who participated had conversations about death as a family. It was postulated that these families had difficulties discussing organ donation as it would involve the death of a loved one.

Research has suggested that there is an increasing need to acknowledge the importance of making death conversations normal for offering opportunities for communities and individuals to see death and dying as a social experience rather than just as a medical issue (Abel & Kellehear, 2016). As such, there have been initiatives such as Death Cafes, Order of a Good Death, and Dying Matters (see Chapter 1.7)

2.6.4.3 Positive conversations about death and dying

Many organisations that focus on death and dying, such as Co-op Funeral Care (2018), Death Cafe (2024), Dying Matters (2024), Hebb (2018), Macmillan

Cancer Support (2017), Manix (2017), Marie Curie Cancer Care (2014), and Royal London (2021), offer resources to encourage people to have conversations about death and dying and have undertaken or supported research.

Studies undertaken by Zajac & Boyatzis (2020), Applebaum & Applebaum (2019), Llewellyn et al. (2017), and Su-Russell et al. (2021) found benefits of talking about death and dying, such as improving relationships and Taylor (2021) found a positive personal change. In addition, Takeuchi et al. (2021) study about reflecting on death during the COVID pandemic found that death reflection positively relates to creativity, a psychological state involving being open, curious, flexible and willing to explore new ideas and perspectives.

Research has suggested that interventions such as dignity therapy (Bentley et al., 2017), life review (Chen et al., 2017; Lan et al., 2017), meaning of life interventions (Guerrero-Torrelles et al., 2017) and education programs (Matsui, 2010; Durlak & Riesenberg, 1991) can improve psychosocial well-being and existential elements of being such as meaning, hope and purpose and quality of life. In addition, conversations about death and dying can offer insights into individuals' experiences, foster empathy and understanding, increase appreciation for life, create greater compassion towards others, and make us aware of our existence's transient nature. For individuals who do not have a life-limiting/shortening illness, conversations and awareness of death could cultivate a sense of gratitude, purpose and authenticity in their lives, providing fulfilment and meaning.

One of the main aims of the death positivity movement is death education, to raise awareness and knowledge about death, dying, and end-of-life care. Educational materials incorporate hospice care, palliative care, funeral planning, and grief support. Providing these resources helps individuals make informed decisions and facilitates open discussions about death and dying. The theories of meaning management theory (Wong, 2008) and gestalt theory (Koffka, 2014), as discussed in Chapter 1, underpin meaning-making, meaning-seeking and meaning-reconstruction to help individuals make sense of their lives and foster personal growth and well-being. These theories focus on the present rather than dwelling on the past or worrying about the future.

2.7 Discussion

Death is a universal event that happens to all and across the lifespan. The scoping review has explored existing literature regarding death and dying conversations in contemporary Western societies. The main aim was to identify the context of the settings where death and dying conversations have taken place and to explore the types of conversations/communications individuals have experienced and their perceived value.

2.7.1 Readiness for discussions about death and dying

The review found that engaging in conversations about death and dying can have positive outcomes. Conversations about death and dying can enhance the individuals' ability to find meaning in life experiences and foster a sense of purpose and personal growth (South & Elton, 2017; Bell, 2023; Trisel, 2015; Yalom, 1980; Frankl, 1986). In addition, conversations about death and dying can encourage individuals to reflect on their values, beliefs, and relationships, thereby developing their understanding of themselves and others (Kinnier et al., 2001; Noyes, 1980). Furthermore, these conversations can help alleviate anxieties related to death and dying, providing individuals with a sense of control and empowerment in facing end-of-life issues (Park & Folkman, 1997; Bauer-Wu & Farren, 2005; Calhoun & Tedeschi, 2006; Pargament & Ano, 2006).

Several studies included in this review identified readiness for discussion about death and dying. For example, von Blankenburg et al. (2020) showed a change in the attitudes of healthy adults, and Taylor (2021) showed that bereavement acted as a catalyst for personal change.

2.7.2 Impact of age on conversations about death and dying

Age can have an impact on the perception and experience of death and dying. Initially, researchers thought that children could grasp the concept of death only around age 10 (Carey, 1985; Piaget et al., 2014). However, shifts in the conceptualisation of death and methodological advancements have led researchers to determine that children's understanding of death develops earlier (Gutiérrez et al., 2020; Rosengren et al., 2014; Speece & Brent, 1984; Ji et al., 2017; Subbotsky, 2020; Brent et al., 1996).

Adolescents understand that death is final and the significance of loss. They also have existential questions about their purpose in life and what happens after death (Waldrop et al., 2004). How they perceive these concepts will impact their beliefs, attitudes, and emotional reactions to death. Their understanding of death and dying will also impact how they manage to deal with grief and support others who are dealing with end-of-life situations.

Adults and older adults' perceptions of death and dying are shaped by their experiences (Kars et al., 2015; Chiu et al., 2012; Keim-Malpass,2012), cultural and religious perspectives (Ando et al., 2010; Harding et al., 2005; Piotrowski et al., 2020; Rego et al., 2020), and societal norms. Adults may start to consider creating legacies and future care plans and engaging in conversations about death and dying with family members. Older adults may consider end-of-life planning due to health issues and try to find peace when thinking about death and dying (Piers et al., 2013. Malcomson & Bisbee, 2009).

2.7.3 Open communication

Open communication about death has been found to improve the quality of interactions between patients, healthcare providers, and family members (Terrill et al., 2018), facilitating shared decision-making, enhancing empathy, and fostering a supportive environment for coping with the challenges associated with life-shortening illness and loss as seen in the literature within this review (Cassano et al., 2008; Chiu et al., 2012; Keim-Malpass, 2012; Willig, 2015). Research has suggested that Interventions (Au et al., 2012) and education (Li et al., 2023) allow for higher-quality discussions about mortality and an increased reduction in their fear of death. What can be suggested from this research is that open communication is crucial to discussions about death and dying. It allows individuals to express their wishes, fears and concerns. Open communication could facilitate conversations among patient families and healthcare professionals to inform decision-making and provide support.

2.7.4 Death awareness

For most people in contemporary Western society, death awareness/thoughts tend to produce adverse outcomes, as seen during the COVID-19 pandemic when there was a perception of scarcity in essential items, including food, result panic to secure household items (Arafat et al., 2020). In addition, Kim et al. (2021), following the manipulation of the participants' thoughts about death and dying, found that Chief Executive Officers (CEOs) lead to engagement in uncertainty-based coping responses (including laissez-faire leaders and impression management (control coping). However, Li et al. (2021) also examined CEOs' responses during the pandemic crisis, finding that the visibility of death during the pandemic resulted in CEOs having a decrease in self-orientation and an increase in other orientations toward making donations from the companies they lead. Studies suggest death and dying conversations could positively impact well-being by providing a more positive route towards a more meaningful life (Vail et al., 2012). Vail et al. (2012) suggested that when individuals directly face or consider mortality, the heightened existential threat can challenge or disrupt their mechanisms for managing fear. This would necessitate an increased effort to consciously reconstruct their perspective on life's meaning and effectively address their mortality. These processes can potentially foster personal development and a transition towards intrinsic objectives and altruistic principles. Moreover, the altered goals, values and time-aware outlook resulting from such confrontations may redirect subconscious fear management mechanisms from self-centred pursuits to more purposeful and communal actions.

Of the studies reviewed, when validated measures/tools were used, there was evidence of improvement in the comfort of people discussing death and dying. However, most studies using validated measures were undertaken in the clinical setting. There appears to be a gap in empirical evidence supporting these potential benefits in non-clinical settings. The review found that the current evidence base is clinically focused and requires additional empirical evidence for non-clinical populations. In reviewing the included articles, it was apparent that while there is a growing recognition of the value of discussing death openly, there remains a need for robust empirical data. Future research could explore the potential advantages of such conversations for the general public and the promotion of how space, relationships and tools to encourage thinking and discourse matter.

2.7.5 The transformational power of conversations about death and dying

Research as reported by Applebaum & Applebaum (2019), Zajac & Boyatzis (2020), Taylor (2021), Keim-Malpass (2012), Willig (2015), Thornton (1991), Machell et al. (2015), Vail et al. (2012) suggested that individuals who are facing life-shortening illnesses can often undergo personal change, which can lead to increased openness and vulnerability within families. This, in turn, fosters a deeper connection and mutual understanding. These accounts emphasise the capacity of illness to prompt introspection, personal growth and a re-evaluation of priorities, leading individuals to find new sources of meaning and purpose in their lives. By sharing people's stories, the literature sheds light on individuals' resilience and adaptability in dealing with death and dying. This highlights the possibilities of illness creating transformations within relationships and personal outlooks.

Among the findings of the studies reviewed were the transformative power of illness on individuals’ lives and perceptions of death and dying. There is a growth of social media platforms that share posts around the benefits of experiencing conversations about death and dying, such as Dying Matters (2024), Motor Neurone Disease Association (2024), Death Café (2024), Order of a Good Death (2024), Modern Loss (2024), A Positive Death UK (2024) and Good Grief Festival (2024). This growth of sharing experiences suggests the need to address the fear of talking about death and dying and instead embrace an openness toward death and dying conversations to improve well-being. Embracing an openness towards discussions about death and dying in the digital world could significantly impact individual well-being by providing avenues for connection, support, and reflection in these virtual spaces. However, this online shift of conversations of death and dying may also raise questions about the authenticity and depth of interactions compared to face-to-face discussions. Whilst virtual platforms can facilitate open discussions, the lack of non-verbal cues and direct human connection in online communication may impact the depth of emotional engagement and interpersonal bonding achieved in in-person conversations. It is evident that there is a need for empirical evidence to substantiate the advantages of discussions of death and dying in non-clinical settings and the value of different platforms for individuals/groups.

2.7.6 Advancing research to understand death and dying conversation

In the UK, public health practice regarding death promotes end-of-life, advanced care planning and bereavement support (NHS England, 2024; Scottish Government, 2023; Welsh Government, 2024; Irish Government, 2022). There is an emphasis on the importance of providing high-quality palliative care, advanced care planning and bereavement support. Successive governments within the UK have emphasised the importance of providing high-quality palliative care to individuals nearing the end of their lives, ensuring there is support that aligns with their preferences and values. Advanced care planning is encouraged to help individuals decide about their future care, including treatment preferences and end-of-life wishes. However, the advanced care plan can focus on the practicalities of dying and physical care needs but has been criticised for not supporting broader psychosocial-spiritual needs (Morrison et al., 2021).

Additionally, NHS England (2024) bereavement support services can help individuals and families cope with the death of a loved one through counselling, support groups and resources. Further research exploring the value of death and dying conversations for all could allow for changes in public health practice. To have these conversations before a person is ill, advocating the potential well-being benefits of engaging in death and dying conversations, ultimately challenging how Western cultures have dealt (or not dealt) with death and dying and related fear could bring about positive cultural change, promoting health and wellbeing across the lifespan.

The studies included in this review shed light on individuals’ attitudes and approaches towards conversations about death and dying regardless of their health status, experiences of bereavement, age or other demographic factors. They reveal that the individual’s ‘Being’ toward death and dying is a complex and multifaceted phenomenon that is influenced by various personal, social and cultural factors. The included studies highlight that a person’s experiences of bereavement, age or other life circumstances can shape their willingness and ability to engage in conversations about death. This emphasises the diverse ways people deal with and make sense of mortality within their lives. Overall, the review emphasised the importance of understanding individuals' unique perspectives and needs when discussing death and dying and recognising that these conversations are deeply personal and can vary widely based on individual experiences and contexts.

An empirical program of work is required that explores in-depth individuals' perceptions of their perceptions and experiences of conversations about death and dying. Exploratory research will provide a foundation for intervention development, develop educational tools/techniques for children, young people, and adults, and encourage changes in practice in general and clinical to support individuals in engaging in meaningful discussions about death and dying. These interventions could promote emotional well-being, enhance communication skills, and foster resilience in general and clinical populations. However, before tools and interventions are created or co-created, there needs to be a greater understanding of what might facilitate conversations and what may be the main barriers in different contexts.

2.8 Review limitations

This review has offered insights into what research has been undertaken around death and dying conversations and what knowledge gaps exist. Some limitations should be acknowledged; a systematic may have provided a more in-depth theoretical discussion through an integrative data synthesis. However, this differs from the aim of this scoping review, as identified earlier in this chapter, and the heterogeneity of the included study would have prevented a data synthesis of the findings. Furthermore, the focus was to explore the range of research undertaken and in what contexts. As with all reviews, there is also a risk of bias in the study selection, data extraction and synthesis, as scoping reviews may involve subjective decisions that could impact the overall findings. This was mitigated through discussion and debates with supervisors across the stages of the review. Findings from scoping reviews may not always be generalisable to broader populations, as the focus of this scoping review was to map the existing literature rather than draw definitive conclusions (Rodger et al., 2024).

2.9 Gaps in the literature

This scoping review has identified a lack of empirical research about conversations about death and dying that are not connected to palliative/end-of-life or formal psychotherapeutic contexts outside clinical contexts. Studies have predominantly reported discussions within clinical contexts, which have been within the palliative and end-of-life care literature and focused on advance care planning. Work remains to be done to develop interventions that support meaning-making and legacy leaving.

This review reveals that more empirical evidence is needed to support the notion that we, the general public and society as a whole, may benefit from having space for open and frank conversations about death and dying; these conversations could improve emotional well-being, enhanced communication skills and greater preparedness for end-of-life issues. In addition, the focus of this thesis is to explore experiences of death and dying conversations. Other potential research areas that arose from the review included:

- Best ways to create space for open conversations about death in preparedness for end-of-life issues among individuals and society as a whole;
- Exploring how topics such as advance care planning, funeral arrangements and healthcare preferences can assist people in making informed decisions, alleviating uncertainty and ensuring their end-of-life wishes are respected
- Evaluating the potential positive outcomes of embracing candid conversations about death and dying and whether promoting such discussions improves the well-being and preparedness of individuals and communities.

In addition, further research about the potential benefit for people to understand the processes of death and dying and to have open conversations about death and dying should have a theoretical underpinning, such as meaning management theory and gestalt theory. Although these theories suggest an openness towards death and dying is beneficial for the human psyche, there is no evidence to explain the mechanisms by which this can be achieved or a consensus on the type of interventions needed to promote death and dying conversations in clinical and non-clinical populations or with children and young people. However, the review has identified techniques that could be further described and assimilated into informing/underpinning theory, such as adopting storytelling techniques.

Additional research is also required that considers a range of religions, faiths, spirituality and cultures as this can impact individuals’ perspectives towards death and dying and individuals’ conversations. Different religious and cultural traditions offer unique perspectives on mortality, the afterlife, and end-of-life practices, shaping how individuals approach and discuss these topics (Ando et al., 2010; Harding et al., 2005; Piotrowski et al., 2020). Understanding the impact of belief systems on people’s views towards death is crucial for developing more inclusive and practical approaches to facilitating conversations about mortality ((Ando et al., 2010; Harding et al., 2005; Piotrowski et al., 2020). Considering a wide range of religions, faiths, and cultures within research can provide insights into the nuanced ways in which individuals from different backgrounds navigate death anxiety and engage in discussions about dying. This inclusive approach can help researchers and practitioners tailor interventions and communication strategies to accommodate diverse beliefs and values, fostering greater cultural competence and sensitivity in end-of-life care and support. While not the focus of this thesis, understanding the intersections between religions, spirituality, culture, and conversations about death is vital for promoting holistic and respectful approaches to addressing individuals’ perspectives and needs surrounding mortality.

Few studies about death and dying conversations have addressed religion, faith, spirituality, and cultures in a non-clinical setting. Individuals have different preferences and levels of readiness to discuss mortality, making a one-size-fits-all inappropriate. Similarly, cultural beliefs and practices can significantly influence how people perceive and respond to interventions. Therefore, a more tailored approach to death and dying conversations must be considered, including religion, faith, spirituality and culture. Additionally, socioeconomic factors such as access to resources, financial constraints, and living conditions could impact the effectiveness of standardised interventions.

Further studies are needed to capture people's lived experiences of conversations about death and dying. This would provide a comprehensive understanding of this complex and sensitive topic. Although qualitative research studies have been undertaken, most have offered descriptive findings and focused on topics adjunct to death and dying conversations. Understanding death and dying conversational experiences and different perspectives and reporting on such may help encourage a cultural shift toward a greater appreciation of the benefits of openness towards death and dying conversations and how this can be achieved. Researchers can uncover the intricate dynamics, emotions and meanings embedded in these interactions by conducting more nuanced qualitative studies that centre on people’s actual encounters with conversations about death and dying. Capturing individuals’ lived experiences can offer valuable insights into discussing such sensitive topics' challenges, benefits and outcomes. This deeper exploration can shed light on the complexities of communication surrounding death, inform the development of supportive interventions and resources, and enhance our understanding of how to facilitate meaningful and constructive conversations about mortality. Expanding qualitative research in this area is essential for capturing the richness and depth of people's experiences with end-of-life discussions. In addition, it is essential to understand the impact that the global pandemic has had on people's perspectives towards death and dying, given that through this pandemic, talk of death and dying in the general media was high. As such, death entered the homes of everyone, and it is of interest to explore the impact this event has had on people's death and dying conversations.

2.10 Rationale for the study

The fear of death or existential distress is a profound and intricate human experience that touches upon our deepest fears, hopes, and existential inquiries. By examining the psychological, cultural, philosophical, and related coping dimensions, studies aim to understand how individuals deal with mortality and seek meaning in the face of uncertainty (Pyszczynski et al., 1997; Pyszczynski et al., 2015; Routledge & Vess, 2018). In contrast, death acceptance involves coming to terms with the inevitability of death and accepting it as a part of life. Death is a multifactorial and complex relationship between attitudes, beliefs, and practices that help individuals face their mortality with bravery, wisdom, and peace via conversations (Wong & Tomer, 2011; Molamohseni et al., 2024). Acknowledging life's impermanence and transience is at the core of embracing death. Psychologically accepting death means recognising mortality, releasing fear and opposition, and fostering a sense of serenity when confronted with the idea of dying.

In uniting the theories discussed in Chapter 1 of terror management theory (Greenberg et al., 1986), meaning management theory (Wong, 2008), and gestalt (Koffka, 2014) and acknowledging the findings of the scoping review, there is the suggestion that as we all must face death at some point, we should be encouraged to engage fully with our emotions, thoughts, and perceptions surrounding our mortality. By acknowledging and integrating all aspects of our experience, we can achieve a sense of closure, acceptance, and completion as we approach the end of our lives. We can also focus on the present moment, our relationships with our environment, the spaces in which we reside, and how we can use them to facilitate meaningful conversations about death and dying.

The study undertaken as part of this thesis will explore the lived experiences of people's conversations about death and dying. Key objectives include to:

- Describe the nature of death and dying conversations individuals have experienced within and outside clinical settings.
- Explore individual’s experiences and perceptions of the death positivity movement.
- Investigate if the global pandemic COVID has influenced individuals’ lived experiences, perceptions and conversations about death and dying.

Understanding the nature and influence of conversations on death and dying is crucial. It involves recognising the timing, settings, and content of these discussions, which can be utilised to develop interventions or educational resources that facilitate honest and open dialogues among individuals.

2.11 Summary

Forty-seven articles were included in the review and appraised with consideration to the review’s aim and related objectives. Seven articles were quantitative, eight were mixed methods, two were action research, and twenty-seven were qualitative. Most studies were undertaken in a clinical setting, with seventeen studies undertaken in various countries, including the UK, USA, and Norway. The review highlighted a need for more empirical evidence to support the notion that we, the general public, may benefit from having space afforded for open and frank discussions about death and dying. The evidence base is clinically focused, with very few empirical studies including non-clinical populations. Most research focuses on clinical end-of-life care, palliative care, or those dealing with a life-shortening illness. Still, even within these studies, there were identified shortcomings concerning initiating conversations about death and dying. The how, when and who and guidance for health professionals to negotiate patient and family needs.

Along with the age and condition characteristics and cultural, spiritual, and family dynamics, more interventional consideration is needed around meaning-making and legacy leaving. The review has identified areas of interest that may benefit future empirical studies, focusing on the review findings, the motivations of the death positivity movement, and the possible value of death and dying conversations for all.

The thesis's methodological choices drive the theoretical framework for this study. However, the theories of terror management, meaning management, and gestalt theory are relevant to the research aim. Along with the key findings of the literature review, these theories will assist with framing the data collection methods. These facets of the thesis will be outlined in the next chapter.

Chapter 3
Philosophical Influences

3.1 Introduction

This chapter details the underpinning philosophical influences of the study. A qualitative interpretive phenomenological approach was adopted and considered the most relevant methodology to investigate individuals’ lived experiences of conversations about death and dying. The rationale for this key decision is outlined, including an overview of qualitative research paradigms and a critical discussion of methodological options within the interpretivist paradigm, including grounded theory and phenomenology. The suitability of a phenomenological approach to meet the research aim is discussed, including an overview of phenomenology as a philosophy and research methodology, detailing the contributions of key scholars. Possible methodological choices that could have been adopted within the interpretive phenomenological approach are offered, including the rationale for the chosen interpretive phenomenological epistemology.

This chapter will start by outlining the epistemological and ontological choices and explaining the different research paradigms. It will then discuss the chosen methodology of phenomenology and detail the prominent scholars of phenomenological philosophy, such as Husserl, Heidegger, Gadamer, Ricoeur, and Merleau-Ponty. Next, it will detail how interpretive hermeneutic and relational phenomenology can be applied to exploring lived experiences of death and dying conversations. The chapter will end with my positionality and a summary.

3.2 Understanding research paradigms

Qualitative research approaches, unlike quantitative approaches, which typically aim to test the causal relationship between variables of interest or measure outcomes, are particularly suitable when research questions do not call for the manipulation of variables. In contrast, qualitative research requires approaches that can make sense of complex situations or explore phenomena, primarily when little is known about a topic (Forrester, 2010; Braun & Clarke, 2013; Langdrige & Hagger-Johnson, 2013). Qualitative approaches enable phenomena to be described and explained, ultimately fostering deeper understandings of the explored phenomena.

Exploring the lived experience of death and dying conversations is a subjective or naturalistic inquiry that necessitates an approach that allows participants to give an account of their own lived experiences. A qualitative approach allows the researcher to understand human behaviour from the participant's perspective. However, designing an enquiry-based study investigating individuals' beliefs and experiences of and about death and dying conversations is challenging because a range of qualitative approaches are available, and each has differing epistemological and ontological underpinnings (Crotty, 2015; Forrester, 2010; Braun & Clarke, 2013; Langdrige & Hagger-Johnson, 2013).

3.2.1 Epistemological and ontological choices

Epistemology postulates the theory of knowledge, posing questions such as 'Do we know what we know?' and 'How can knowledge be made more reliable?' (King & Horrocks, 2010; Creswell, 2013; Crotty, 2015). Epistemology is a branch of philosophy dating back to the time before Socrates, focussing on what constitutes knowledge, how this knowledge can then be acquired or produced, and how easily the knowledge can be transferred to other contexts (Creswell, 2013). Epistemology is a way of looking at and making sense of the world, influencing how a research design is framed, which, for this study, explores how best to discover knowledge from participants' conversations about death and dying. Ontology is the study of 'Being' and concepts of existence and reality, asking questions such as 'What happens to us when we die?'; 'Is there a God?'; and 'Is there such a thing as objective reality?' (Creswell, 2013). Ontology focuses on the nature of 'Being' and existence. These abstract concepts are highly relevant to this study and within the context of death, dying, religion, and spirituality.

Understanding the ontological and epistemological perspectives of qualitative research approaches and their possible application to this study assisted in making an informed choice about the study design. Crotty (2015) postulates that a researcher must consider four questions when choosing the most appropriate research design:

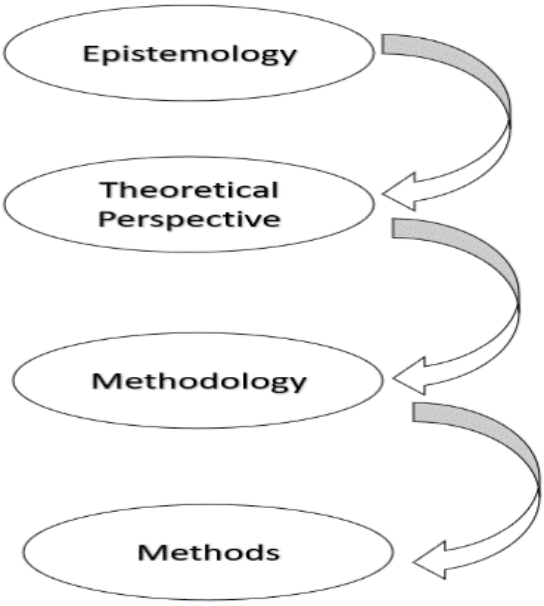
1. What is my theoretical perspective? What philosophical stance have I used to inform the methodology that will provide the context for my processes?
2. What is the epistemological stance that informs my perspective?

3. What methodology am I considering: what is my strategy, plan of action, design and processes underpinning my choice, and use of a particular method for data collection/analysis?
4. What methods do I propose to use, and are they congruent with the chosen methodology, including methods or procedures I will use to collect and analyse the data?

Crotty (2015) proposed that epistemology, theoretical perspective, methodology, and methods are interlinked and that making a decision in one area impacts others (Figure 3.2.1).

Figure 3.2.1

Link between perspectives, methodology and methods



Considering these questions can facilitate deeper thought-making processes and greater clarity in decisions.

3.2.2 Epistemological and ontological limitations

Reducing complex lived experience phenomena to parts, such as type or junction, or elements of death and dying conversations would have resulted in an oversimplification of reality, potentially overlooking important nuances and intricacies and the multiple facets that influence these conversations. In addition, the researchers' preconceptions, personal beliefs, or cultural backgrounds can introduce bias into the research process, influencing data collection, interpretation and analysis. Certain phenomena, such as beliefs about death or spiritual experiences, may be challenging to quantify or measure using traditional quantitative research methods, limiting the ability to capture the full complexity of these aspects.

Research involving sensitive topics like death and dying requires careful consideration of ethical principles, such as ensuring informed consent, maintaining confidentiality and protecting participants' well-being. Regarding ethical concerns, particularly when exploring sensitive topics like existential fears or cultural beliefs about death, researchers must be able to navigate ethical dilemmas related to privacy, respect for participants' beliefs and the potential emotional impact of the research. Understanding and managing these epistemological and ontological limitations is essential for conducting rigorous and ethical research that accurately captures the complexities of death and dying.

Researchers often require a nuanced approach that combines qualitative methods, reflexivity, and ethical considerations to capture the multifaceted nature of conversations about death and dying. In addition, to effectively address the research question or aim, researchers must adopt appropriate methods, reflexivity, and ethical practices.

Research findings on topics such as death and dying have implications for policy development in areas such as healthcare, social services, and education. Researchers must consider how our work may inform or influence policy decisions and societal practices.

3.2.3 Communicative contexts differ

It may be initially conceived that contexts that influence discussion around death and dying are similar. The processes engaged in by individuals are processes that could be accessed or evaluated by structured or standardised methods. However, there are individual differences that would make it difficult to use quantitative methods to evaluate context, content and experience. By the same token, creating controlled, non-complex communicative environments to explore conversational predictions is impossible. There are likely to be many factors outside of the communicative context that influence the focused conversation around death and dying. These include, for example, factors that have led to the conversation or motivation for conversation and experiences of influence that impact the interpretation of conversations within and outside the conversation. These differences would be difficult to predict, measure or recreate across similar contexts, not least because individuals have different life experiences, relationships and perceptions of events. As such, we can appreciate elements of shared experience and understanding, but it can also be acknowledged that we each may take away something different from reaching an understanding of the phenomenon. Death and dying conversations are events that may encourage well-being for different individuals. There may be learning elements for both policy and practice that can be advocated from this work. Still, there will be limitations as to the extent to which we can generalise or adopt arguments or recommendations for context, content and experience in any directives because we all experience this phenomenon from different developmental and world views/vantage points. It is not the aim of this research to decipher how and in what ways we should instruct conversations about death and dying in the same way we may prescribe medication but to explore in what contexts death and dying conversations happen, what the nature of these conversations are, what individuals take from them and how they experience the communicative event at the time and over time.

3.2.4 Researcher positionality

The researcher's beliefs about the context in which the research will take place have also influenced the choice of methodology, the methods used to gather data, and the study outcomes.

In considering the nature of reality as being interpretive, subjective, and different for each individual, there is an ambition with this work to try to understand the phenomenon from the individual’s perspective. Many theories can be drawn upon in taking this view, and each is at odds with positive methods. The purpose of this research is to understand the lived experience of death and dying conversations openly instead of trying to control or predict outcomes. As such, interpretive methodologies are most appropriate. See also Section 3.6 for further researcher positionality.

3.2.5 Positivist paradigm

The positivist paradigm, traditionally the dominant discourse within scientific research, assumes a definite relationship exists between our perceptions of the world and the actual world (Langdridge, 2004; Forrester, 2010; Creswell, 2013; Langdridge & Hagger-Johnson, 2013). The positivist paradigm is closely aligned with empiricism in that there is a separation between the observation, the observer and what is being observed, requiring unbiased data collection and analysis (Langdridge, 2004; Forrester, 2010; Creswell, 2013; Langdridge & Hagger-Johnson, 2013). Positivism purports that research should only focus on what can be observed, using scientific methods with controlled variables with the researcher distancing themselves from the research process in an attempt to reduce bias (Langdridge, 2004; Forrester, 2010; Langdridge & Hagger-Johnson, 2013). However, following critiques by scholars, including Popper (2002), Khun (1970), and Weber (1978), came the emergence of post-positivism. While adopting scientific methods, post-positivism acknowledges that researcher bias cannot be eliminated entirely and that all decisions and choices influence the research design and methods adopted. Central to drawing on this paradigm/approach, researchers do not attempt to control for and remove subjective influences but account for these when discussing their findings. This paradigm is congruent with quantitative designs and methods that use reliable and valid tools and statistical analysis. However, the post-positivism stance does not lend itself to qualitative research, including my worldview, as experiential variables will always impact the research processes. In addition, a quantitative design would not meet the study’s aims; exploring the conversations that people have about death and dying is subjective. The participants' experiences are valuable to the study’s aim and cannot, and should not, be controlled. Seeking to understand their lived experiences and perceptions is not congruent with the positivism/post-positivism paradigm.

3.2.6 Interpretivist paradigm

Some enlightened scientists, Max Webber (1864-1920), Wilhelm Dilthey (1833-1911), Wilhelm Windelband (1848-1915) and Heinrich Rickert (1863-1936), re-evaluated their epistemological views during the second half of the twentieth century. These scholars started challenging the well-established positivist paradigm, postulating that humans construct meanings within their everyday lives, individually and socially, and are part of reality and the subjective reality of those experiencing them (Crotty, 2015). They postulated that the researcher’s knowledge could add to the research process and not diminish it. From this understanding, the interpretivist paradigm came to fruition. Central to interpretivism is considering how individuals construct knowledge and understanding as they interpret their lived experiences of living every day. The interpretive perspective is congruent with knowledge being created from experiences. Therefore, interpretivism is subjective and bound to the natural contexts in which people live; it is about people's values, individuality, culture, and society. The interpretivist paradigm is not universal, not generalisable, and is ideographic and relative to each situation, with no interpretation being more valuable than another (Williams, 2000). The researcher is responsible for producing a narrative with rich descriptions of participants’ accounts, providing context, and offering explanations to assist the reader in exploring the relevance of the study findings to their work/ area of practice.

Within interpretivism, there are several assumptions (Alharahshel & Pius, 2020):

1. Multiple realities exist - as humans, we live in one world, but each person has their interpretation of that world;
2. The social and cultural contexts individuals inhabit shape each person’s version of their reality;
3. Interpretations are not neutral - all findings within qualitative research can be influenced by the beliefs and values that the researcher brings into the research;
4. Bias exists across research approaches and is difficult to eliminate, but it should be accounted for; researchers bring their experiences, ideas, prejudices, and personal philosophies to every study, which, if accounted for in advance of the study, enhances the transparency of possible research bias.

3.2.7 Interpretivist qualitative approaches

To understand the lived experience of death and dying conversations, a plethora of qualitative approaches underpinned by different epistemological and ontological positions, each drawing on the interpretivist paradigm, could have been adopted, for example, grounded theory (Glaser & Strauss, 1967) and Phenomenology (Smith et al., 2022).

- Grounded theory is suitable for exploring phenomena where a new perspective would be beneficial or in an under-researched area. The broad aim of Grounded Theory is to build a theoretical model or conceptual framework generated from the data (Glaser & Strauss, 1967). Grounded theory has sociological roots, emphasising the understanding of social processes via social constructionism (Burr & Dick, 2017) and symbolic interactionism (Blumer, 1986). A possible question grounded theory would underpin is, 'How do people discuss death and dying topics? While it could provide valuable insight into this area, it would not address this thesis, which aims to explore individuals' conversations regarding death and dying and the meaning they attach to the subject. Furthermore, the purpose was not to develop a theory to be tested but to understand the subjective experience, engage others in understanding how death and dying conversations are perceived and experienced, and explore both the idiographic and shared elements of those perceptions and experiences. Therefore, a grounded theory approach is limited in its applicability to the study.

- Phenomenology is a research approach that explores lived experience and the meanings individuals attach to everyday life experiences (Smith et al., 2022). Phenomenology moves away from looking at the object just as it is and attempts to ascertain the meaning and structure of phenomena to understand its unique significance to the individual experience without a causal explanation. Therefore, a phenomenological approach is most suited to the aims of this study, as it would allow me to explore the conversations people have about death and dying that stem from their subjective lived experiences.

3.3 Phenomenology as a philosophy and research methodology

Phenomenology is a philosophy that can be used to understand human experience (Langdridge, 2007; Suddick et al., 2020; Smith et al., 2022). Phenomenology as a research methodology aims to explore experience without focusing on predetermined theories. Phenomenology and key phenomenological concepts can be drawn on to assist researchers in understanding lived experiences so that they can describe and offer an understanding of phenomena in new and different ways (Langdridge, 2007; Suddick et al., 2020; Smith et al., 2022).

Phenomenological philosophy reasons that a person (subject) cannot be removed from the real world (object). The individual’s real-world perception interconnects the subject and object. In addition, it is further noted that the individual’s perception may be modified or adapted depending on surrounding contexts and emotions (Moustakas, 1994; Langdridge, 2007). Individuals view the world differently and will attach different meanings to their experiences. Using a phenomenological methodology helps the researcher understand a phenomenon, such as death and dying, from an individual’s worldview.

Phenomenology is a branch of philosophy that has been adapted over the years from the original version, known as Descriptive Phenomenology, founded by Edmund Husserl (Langdridge, 2007; Smith et al., 2022), to Existential Phenomenology influenced by individuals such as Martin Heidegger, Jean-Paul Sartre, Simone de Beauvoir and Maurice Merleau-Ponty and Hermeneutic Phenomenology by Hans-Georg Gadamer, and Paul Ricoeur (Smith et al., 2022). Phenomenology continues to develop to this day, but the contributions of its critical scholars are outlined below, offering descriptions of their philosophical contributions and how they relate to research methodology. When phenomenology is applied to death and dying conversations, it can help us to explore and make sense of an individual’s experiences and emotions surrounding mortality.

3.3.1 Edmund Husserl (1859-1938)

Husserl is considered the forefather of phenomenology (Langdridge, 2007; van Manen, 1998; Moustakas, 1994). Husserl was an early twentieth-century German philosopher who disagreed with the idea that only objective knowledge was credible. Husserl believed that gaining a subjective understanding of the individual’s lived experience was fundamental to understanding how the individual engages with the world. He suggested that researchers focus on each event or situation ‘in its own right’ and not fit these things into any pre-categorisations the person may have created. Husserl believed the individual should fully engage consciously in each event or situation (Husserl, 1999; Langdridge, 2007; Smith et al., 2022; Rodriguez & Smith, 2018).

A fundamental tenet of Husserl's descriptive phenomenology is that of intentionality. Franz Brentano first used the concept of intentionality; in existentialist terms, it is an interdependence of the subject and the world (Langdridge, 2007; Crotty, 2015; Smith et al., 2022). Intentionality brings to the forefront the interaction between subject and objects, i.e., people engaging in their world, and it is in this interplay that meaning is created. Intentionality is fundamental to the philosophy of phenomenology (Langdridge, 2007; Crotty, 2015; Smith et al., 2022). However, in phenomenology, intentionality does not mean how an individual intends to do something but instead having the intention to be conscious of their surroundings and actions. Husserl, a student of Franz Brentano's, built on his mentor's work by introducing the concepts of noesis, noema, and epoché (Langdridge, 2007; Crotty, 2015; Smith et al., 2022). Noesis and noema refer to meanings; noesis is how something is experienced, for example, the act of feeling or thinking, while noema is how something is experienced (Langdridge, 2007). Husserl suggests an individual will notice an object, i.e. the real world, the thing being observed, and then give meaning to that object, giving it some form of personal meaning (Langdridge, 2007; Crotty, 2015; Smith et al., 2022). individuals bring their conscious awareness (intentionality) into the experience, developing a noematic interpretation. A critical edit of Husserl's approach is Epoché. Epoché is the process by which a researcher aims to set aside their thoughts, bracketing any preconceived ideas they may have on the subject being investigated (Langdridge, 2007; Moustakas, 1994). Husserl believed researchers should describe the explored topic without imposing their personal views and assumptions. However, contemporary phenomenological researchers question if this is achievable (Langdridge, 2007; Crotty, 2015; Smith et al., 2022). In Husserl's earlier work, notions of being conscious and reflexive about the lived experience were advanced and have subsequently influenced many renowned phenomenological researchers such as Heidegger, Gadamer, Ricoeur and Merleau-Ponty.

3.3.2 Martin Heidegger (1889-1976).

Heidegger was a German philosopher and Husserl's student. However, his philosophical stance diverged from Husserl's, and he developed phenomenology further by focusing on the more existential aspects of experience (Heidegger, 2010). He believed individuals could not be separated from their lived worlds, making bracketing impossible. Heidegger's phenomenology focuses on the person, including cultural and social circumstances, believing that social and economic factors influence how individuals relate to their world, their intentionality, and how meaning is constructed. He believed every person sees their world differently, as they have been shaped by their culture, faith, and social interactions, which he called 'dasein' (Heidegger, 2010). The concept of 'dasein' refers to understanding the meaning of the phenomena in its entirety, requiring the researcher also to be part of the research. Heidegger is credited with embedding hermeneutics, the art or science of interpretations, into phenomenology. The interpretations of both the researcher and the participant become part of the research. Consequently, adopting Heidegger's phenomenology, the researcher must accept their role in interpreting the data and be aware and reflexive throughout the research process.

3.3.3 Hans-Georg Gadamer (1900-2002)

Gadamer was the leading philosopher within Hermeneutics. His most famous published work, Truth and Method (2004), established discourse as the primary means of arriving at truth and agreement. He believed that theoretical frameworks were constructed through language. Like Heidegger, Gadamer regarded language as the house of 'Being' and how understanding is achieved (Gadamer, 2004; Langdridge, 2007; Crotty, 2015; Smith et al., 2022). Language is the fundamental mode of 'Being' and the all-embracing form that constitutes our world. Gadamer believed that true understanding is attained through engaging in dialogue and conversation. He stressed the significance of conversations with others as they facilitate individuals sharing their insights and viewpoints (Gadamer, 2004). In addition, meaning cannot be extracted from a text or other object but rather from an event and experiences that have occurred and through and in interpretation that transforms the interpreter. Hermeneutics for Gadamer is Dasein's mode of 'Being'. Gadamer believed that our preconceptions and biases shape our understanding and that interpretation requires a fusion of the perspectives between the interpreter and the object of interpretation (Gadamer, 2004).

3.3.4 Paul Ricoeur (1913-2005)

Paul Ricoeur was a French philosopher known for his contributions to the further development of hermeneutics and phenomenology (Langdridge, 2007; Crotty, 2015; Smith et al., 2022). His philosophical stance can be characterised as a blend of hermeneutics and phenomenology approaches. Ricoeur emphasised the interpretation of texts and understanding of human existence through language and narrative. He believed that our understanding of ourselves and the world is shaped by the stories we tell and the meanings we attribute to them (Langdridge, 2007; Crotty, 2015; Smith et al., 2022). Ricoeur explored the concept of "the hermeneutics of suspicion", where phenomena are critically examined for hidden meanings and ideologies within texts and societal structures. Overall, Ricoeur's philosophy centred on interpreting the meaning of the narrative and the role of the human experience in shaping the narrative (Langdridge, 2007; Crotty, 2015; Smith et al., 2022).

3.3.5 Maurice Merleau-Ponty (1908-1961)

Maurice Merleau-Ponty was a French philosopher. About phenomenology, he rejected the mind-body dualism and emphasised the embodied nature of human consciousness (Langdridge, 2007; Crotty, 2015; Smith et al., 2022). He believed that our lived experiences shape our understanding of the world and that perception is a fundamental aspect of our existence (Langdridge, 2007; Crotty, 2015; Smith et al., 2022). Merleau-Ponty argued that our understanding of the world is fundamentally intertwined with our bodily experiences. He focused on the interplay between perception and embodiment and how we make sense of the world through bodily experiences (Langdridge, 2007; Crotty, 2015; Smith et al., 2022).

In summary, Husserl, Heidegger, Gadamer, Ricoeur, and Merleau-Ponty are influential philosophers who significantly contributed to the development of hermeneutics and phenomenology. Whilst each philosopher offers a unique understanding of phenomenology, philosophical stances and methodologies, they all share an inherent belief in interpretation, knowledge, and the complexities of human experience. Husserl and Heidegger laid the groundwork for phenomenology.

Gadamer and Ricoeur focused on dialogue and narrative, respectively, and Merleau-Ponty explored embodied perception. They encouraged qualitative research to consider how humans are immersed in a world of objects, relationships, and language.

3.4 Interpretive hermeneutic phenomenology and its application to exploring lived experiences of death and dying conversations

Interpretive hermeneutic phenomenology is an approach within phenomenology that focuses on understanding and interpreting human experiences within their cultural, societal, and historical contexts. The emphasis is on the importance of interpretation, language, and the social world in shaping our understanding of lived experiences (Langdridge, 2007; Crotty, 2015; Smith et al., 2022).

When applied to exploring conversations about death and dying, interpretive, or otherwise termed hermeneutic phenomenology, is an appropriate methodology for understanding the meaning and significance of these experiences for individuals and communities. This approach would enable the cultural, social, and personal factors that influence our understanding of death and dying to be accounted for.

Researchers who may use interpretive phenomenology to explore the lived experience of death and dying conversations would engage in in-depth interviews and analyse textual, oral or visual data to explore the lived experiences, beliefs, and emotions surrounding death and dying conversations. The approach would facilitate the researcher to explore how individuals make sense of death, the language and narratives used, the cultural and societal influences on these conversations for the individual, and the impact of these discussions on individuals' experiences of grief and loss.

By adopting an interpretive phenomenological approach, I aim to understand better the complex, multifaceted, and nuanced nature of death and dying conversations, recognising the subjective and contextual aspects that shape these experiences for individuals. A more nuanced exploration of the lived experiences and meanings associated with death and dying could result in a broader understanding of the human experience in the face of mortality.

As a researcher exploring lived experience, I can adopt several methodologies aligned with interpretive phenomenology. These include the interpretive relational approach of Findlay (Findlay, 1967), the four-lifeworld existentials and related work of van Manen (van Manen, 2016), Smith’s Interpretative Phenomenological Analysis (Smith et al., 2022) and Langdridge’s critical narrative analysis (Langdridge, 2007).

3.4.1 Relational phenomenology

Relational phenomenology is the philosophical perspective developed by South African philosopher John Niemeyer Findlay (Findlay, 1967). His approach to phenomenology combined elements of interpretive and relational philosophies. Findlay (1967) emphasised the importance of interpretation and understanding in human relationships and the relational nature of human existence. Findlay argued that our understanding of others and the world is shaped by our interpretive frameworks and the meaning we attach to experiences. Relational phenomenology is an approach that focuses on understanding and exploring the lived experiences of individuals and the interconnectedness between individuals, social context and the world in which they exist (Findlay, 1967). Using this framework, which highlights the importance of relationships and social interactions in shaping our experiences and meanings, I could explore and analyse the relational aspects of the participants’ conversations about death and dying. Capturing the rich and nuanced aspects of how individuals perceive, interpret, and make sense of their death and dying conversations with others and how this interaction influences their lived experiences is central to this study.

3.4.2 van Manen

Max van Manen is a prominent phenomenologist known for the concept of "lifeworld existential". van Manen identified four key lifeworld existentials that shape human experience, the first being temporality (van Manen, 1998; 2016). Temporality refers to the experience of time and how it can influence our understanding of the world. van Manen emphasised the importance of understanding lived experiences' temporal dimensions, including the past, present and future, and how they shape interpretations and actions (van Manen, 1998; 2016). The second existential is spatiality, which is the experience of space and how it influences perception and engagement with the world. van Manen believed that our experiences are situated within specific spatial contexts, and these contexts can influence our understanding and interactions. The third existential is corporeality, the embodied nature of human existence. van Manen highlighted the significance of bodily experiences and sensations in shaping understanding and engagement with the world. The bodily experiences and capabilities can influence how individuals perceive, act, and make sense of their surroundings. The fourth and final existential is relationality, the interpersonal and social dimension of human existence. Central to relationality is the importance of relationships and social interactions in shaping experiences and understanding, the relationships with others, and broader social and cultural contexts that influence interpretations and meanings (van Manen, 1998; 2016).

van Manen's work focuses on understanding the lived experiences of individuals and the lifeworld contexts in which these experiences occur. He encourages researchers and practitioners to explore these Lifeworld Existentials to understand human experiences better and inform meaningful and contextually relevant interventions or practices (van Manen, 1998; 2016). van Manen's lifeworld existential approach is a phenomenological research methodology that focuses on understanding the lived experiences of individuals within their lived world. It emphasises the existential aspects of human existence and the meaning-making process (van Manen, 1998; 2016).

Within van Manen’s framework, I could explore individuals' subjective experiences and perspectives regarding their conversations of death and dying within their lived world. I hope to uncover the deeper meanings and existential themes that emerge from participants, recognising the complexity and uniqueness of their experiences and how they connect to the Four Lifeworld Existentials. It could provide a rich and nuanced understanding of how the participants make sense of their experiences of death and dying conversations.

3.4.3 Interpretative phenomenological analysis

Jonathan Smith is a researcher who has made significant contributions to the field of Interpretative Phenomenology. In particular, he is known for his work on developing and refining Interpretative Phenomenological Analysis IPA) (Smith, 2004, 2007; Smith et al., 2022). Throughout his work, there is an emphasis on the need for multiple readings and interpretations of the data to uncover the rich and nuanced meanings of the phenomena being explored, as attributed by participants (Smith, 2004, 2007; Smith et al., 2022). In addition, he believes in the importance of reflexivity in the iterative research process, encouraging researchers to critically reflect on their assumptions, biases, and interpretations that may influence the analysis.

IPA is typically used in psychology and the social sciences, and more recently across healthcare disciplines, to explore and understand individuals' subjective experiences and the meanings they attach to those experiences. IPA has been informed by concepts from three key areas of philosophy: phenomenology, hermeneutics and idiography (Smith et al., 2022).

IPA is a suitable method when exploring complex and subjective phenomena, such as the lived experience of death and dying conversations. It can provide a rich and nuanced insight into participants' lived experiences and allow for a deep understanding of the meaning-making processes that shape their subjective realities. The analysis in IPA involves a rigorous interpretative process, where researchers immerse themselves in the data and develop a reflective and iterative process of coding and interpretation. The aim would be to uncover the unique and individual meanings that participants attribute to their experiences and to understand the broader themes and patterns that develop across participants concerning conversations about death and dying.

3.4.4 Critical narrative analysis

Darren Langdridge is a British psychologist known for his work in qualitative research methods and LGBTQ+ psychology. Langdridge (2007) emphasised the importance of understanding the power dynamics and social structures that influence the production and interpretation of narratives. He believed that dominant narratives could marginalise certain groups or reinforce social inequalities.

Critical narrative analysis (CNA) is widely used in the social sciences and humanities to examine and interpret narratives with a critical lens. It involves analysing and deconstructing narratives to uncover underlying power dynamics, ideologies, and social structures. The goal is to understand how social, cultural, and political contexts shape narratives (Langdridge, 2007). CNA allows researchers to explore how narratives reflect and perpetuate social inequalities, dominant discourses, and marginalisation. CNA allows for examining the language, themes, and storytelling to uncover hidden meanings and power dynamics (Langdridge, 2007). This approach involves questioning and challenging dominant narratives, exposing contradictions, amplifying marginalised voices and perspectives, and seeking awareness of how narratives can reinforce or challenge existing power structures and social norms (Langdridge, 2007).

CNA could be undertaken to analyse individuals' discussions about death and dying, question the dominant narratives, identify silences or omissions, and explore alternative perspectives as well as thematic content. In addition, CNA would support reflexivity and reflection on my positionality and biases and the broader social-political context in which the narratives are situated (Langdridge, 2007). CNA would allow me to challenge power imbalances, expose any social injustices and promote social change concerning the conversations people have about death and dying. It would allow for a deeper understanding of how the narratives are constructed, negotiated, and influenced by societal factors, ultimately providing a more nuanced and socially aware interpretation of the conversations people have about death and dying.

3.5 Methodological choices for the current study

The current study draws on interpretive phenomenological epistemology. This approach offers a way of exploring individuals’ lived experiences and perceptions, resulting in an in-depth understanding of the participants’ subjective experiences and uncovering rich and nuanced insights that may not be captured through other research approaches (van Manen, 2016; Smith. 2004). Interpretive phenomenology focuses on how individuals make sense of their experiences, beliefs, and emotions, shedding light on the significance and personal meanings attributed to phenomena being explored, such as conversations about death and dying. The approach allows for data collection and analysis flexibility, allowing me to `capture participants’ unique perspectives. By centring on human experiences and perception, interpretive phenomenology offers a humanistic lens that values individual choices, emotions, and interpretations, fostering empathy and understanding in research (van Manen, 2016; Smith. 2004).

Findlay's relational phenomenology makes sense of individuals' death and dying conversations and how interactions influence their lived experiences (Findlay, 1967). Relational phenomenology offers several advantages over traditional approaches, such as focusing on the interconnectedness between individuals, their experiences and their world (Findlay, 1967). This approach highlights the importance of relationships in shaping perceptions, meanings, and understanding of phenomena such as conversations about death and dying. Exploring experiences within relational contexts and the influence of social, cultural, and interpersonal dynamics on individuals' lived experiences, providing a more holistic understanding of the complex phenomena of conversations about death and dying, can be captured. Relational phenomenology encourages reflexivity and acknowledges the co-creation of knowledge between me, the researcher, and the participants. This collaborative approach fosters mutual understanding, trust and respect in the research process. The approach prioritises ethical considerations by recognising research relationships, relations and ethical dimensions. Using relational phenomenology allows me to be attentive to power dynamics, respect participants' autonomy, and prioritise ethical engagement throughout the research process.

In addition, van Manen's lifeworld existentials will be drawn on to explore individuals' meaning-making and existential themes, to make sense of their experiences of death and dying conversations and how these experiences then shape their understanding of themselves and the world around them (van Manen, 1998; 2016). van Manen's lifeworld existentials provides a framework of phenomenological research emphasising key aspects of human existence, such as a holistic understanding of the participant's lived experiences. The four lifeworld existentials – lived body, time, space, and human relation, offer a comprehensive lens to explore and understand human experiences (van Manen, 1998; 2016). By focusing on these fundamental aspects of human existence, using this framework allows me to uncover deep insights into individuals' lived experiences, perceptions, and meanings related to the phenomena of conversations about death and dying. The framework balances universal human experiences with the unique and individual ways people encounter and make sense of these existential dimensions, allowing for insights and nuanced understanding of lived experiences. The approach encourages me as a researcher to be reflexive and self-aware, fostering a deeper understanding of my perspectives, biases, and assumptions in relation to the lifeworld existentials and the experiences of the participants.

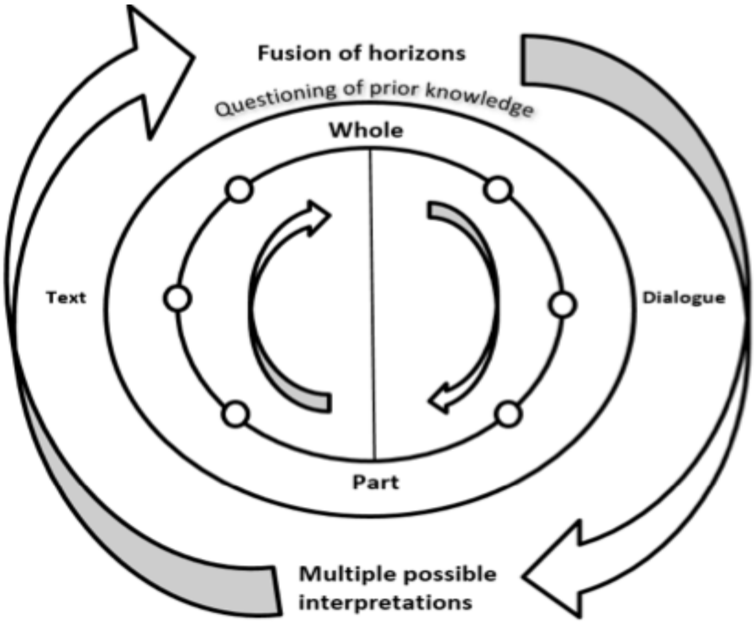
Drawing on these methodologies will allow me to be flexible in my interpretive phenomenological approach to researching the phenomena. From my worldview, it will provide me with a more meaningful, nuanced interpretation of the data. I will also draw upon key elements of phenomenological inquiry, including the Hermeneutic circle, imaginative dwelling and horizontalisation, to help me understand and interpret the data derived from the reported lived experiences.

3.5.1 Hermeneutic circle

The hermeneutic circle is the theory and methodology of interpretation. It describes the iterative process of understanding a phenomenon by moving between its parts and the whole (Figure 3.5.1).

Figure 3.5.1

The hermeneutic cycle (Peat et al., 2019)



The premise of the hermeneutic circle is that understanding begins with an initial interpretation of the whole, then is refined and adjusted as the interpreter or researcher engages with the individual parts or details. Conversely, the overall context and interpretation influence the parts' understanding. In this circular process, the researcher continually moves between the parts and the whole, refining their understanding and gaining deeper insights. This is an ongoing and dynamic process where understanding is developed through a reciprocal relationship between the parts and the whole of the data/experiences and perceptions reported (Suddick et al., 2020).

3.5.2 Imaginative dwelling

Imaginative dwelling refers to exploring and understanding lived experiences by engaging in imaginative reflection or ‘dwelling’ on them (Finlay, 2014). It involves the researcher actively immersing themselves into the experience and using their imagination to recreate and explore its various aspects, dimensions, and nuances. This allows for a deeper understanding of the experience and uncovers hidden meanings, intentions, and structures that may not be immediately apparent.

3.5.3 Horizontalisation

Horizontalisation involves suspending preconceived assumptions and biases to approach a phenomenon with openness and neutrality. It consists of setting aside preexisting knowledge or interpretations and engaging in a direct, nonjudgmental exploration of the phenomenon as it presents itself in conscious experience. This process allows for a fresh and unprejudiced examination of the phenomenon, enabling a more accurate and nuanced understanding (Moustakas, 1994).

3.6 Researcher positionality

Due to the subjective nature of qualitative enquiry, researcher positionality plays a critical role in the research process and accounting for decisions made during data collection, analysis, and interpretation (Creswell, 2013; Creswell & Miller, 2000). My personal beliefs, values, and experiences can potentially introduce bias in how the data is analysed and the findings are interpreted. Awareness of my positionality is crucial to accounting for my biases and their impact on study findings. Acknowledging and reflecting on my positionality through reflexivity allows me to be transparent about my perspectives and biases. This enhances the credibility and trustworthiness of the research process and findings. The theoretical frameworks, my background, and my methodological approaches have all been shaped by my positionality, such as I feel death is part of life. Understanding and accepting that I will die at some point allows me to grow and live in the present without regretting the past or worrying about the future. Refer to Chapter 1, section 1.2 for a more detailed reflection of my position. These beliefs/views may influence patient rapport and data quality collected. In addition, having to be mindful is essential for upholding ethical standards in qualitative research. Consideration must be given to power dynamics, confidentiality and respect for the participants' voices in the data interpretation. Such as being mindful of how my position of authority may impact the responses and ensuring that participants feel empowered and respected through the process.

3.7 Summary

This chapter has outlined the appropriateness of a qualitative design for the research, which aims to explore the lived experiences of death and dying conversations. A range of methodological options within the interpretivist paradigm that could have underpinned the study are outlined. There are several similarities and differences between Findlay's Relational phenomenology, van Manen's Four Existentials, Smith's IPA and Langdridge's CNA. They all aim to explore and understand subjective experiences and meanings. They focus on the lived experience, with each approach placing importance on studying the lived experiences of individuals and the meanings they attach to the experiences. All four emphasise context and recognise the significance of the social, cultural, and historical contexts shaping individuals' experiences and interpretations. However, CNA examines the narratives with a critical lens, focusing on power, social inequalities, and cultural ideologies. In comparison, IPA emphasises seeking to understand the individual's subjective experience and interpretation of their lived experiences. Lifeworld existential work focuses on the existential dimension of human existence, and relational phenomenology focuses on the importance of relationships and social interactions.

Drawing on the work and methods of Findlay's Relational phenomenology and van Manen's lifeworld existentials, the chosen interpretive phenomenological approach requires me to engage in related and detailed procedural processes. The related highly organised but not prescribed methods are outlined in the next chapter. In using an interpretive phenomenological approach, I aim to stay close to and preserve the lived experiences of conversations about death and dying, as described by the participants themselves, and explore their meaning-making related to these experiences, also acknowledging my worldview through the process of interpretation.

Chapter 4
Methods

4.1 Introduction

This chapter presents and justifies the methods employed to ensure the study's overarching aims and objectives were met. The design, sample and recruitment strategy, data collection and analysis methods are detailed. The steps taken to ensure the rigour and quality of the study are highlighted, followed by a discussion of the ethical considerations, in particular issues relevant to undertaking research deemed to be 'sensitive' and those applicable to the ethical conduct of the study.

4.2 Aims and Objectives

The overarching aim was to explore individuals' lived experiences of death and dying conversations. The related objectives were to:

- Describe the nature of death and dying conversations individuals have experienced within and outside clinical settings;
- Explore individuals' experiences and perceptions of the death positivity movement;
- Identify whether the global pandemic COVID has influenced individuals' lived experiences, perceptions and conversations about death and dying.

4.3 Design

As outlined in Chapter 3, the study has adopted a qualitative design, drawing upon interpretive phenomenology to explore the lived experience of conversations about death and dying.

4.4 Sample selection

Recruiting adult participants with experience of death and dying conversations was central to achieving the study's aims. The most common research sampling strategies, with terms often used interchangeably, are purposeful, selective, and theoretical sampling (Palankas et al., 2015; Moser & Korstjens, 2018).

The distinction between these sampling strategies appears to relate to whether sampling criteria are flexible and adapted as data collection progresses and in response to preliminary data analysis. Purposive sampling involves predetermined selection criteria, whereas theoretical sampling allows for criteria refinement based on initial data analysis and as the study progresses (used within grounded theory studies). Both purposive and theoretical sampling methods aim to identify participants with relevant experience or interest in the phenomenon under study. Additionally, supplementary techniques like snowball sampling, where participants refer to or introduce others, can be integrated into purposive sampling to locate traditionally hard-to-reach participants (Palankas et al., 2015; Moser & Korstjens, 2018).

Purposive sampling is commonly used in phenomenological research, allowing the researcher to explore the topic in depth by selecting participants who have experienced the phenomenon. By choosing participants who can offer valuable insights into the research topic, purposive sampling helps researchers gather meaningful data that aligns with the study's phenomenological focus on understanding subjective experiences and meanings. In the current study, purposive and homogeneity sampling was adopted to yield information-rich data by identifying individuals with experiences of conversations about death and dying. Homogeneity allows the selection of participants with similar characteristics or experiences relevant to the research objectives. This provides a way to gain in-depth insights into a particular group (Forrester,2010; Braun & Clarke, 2013; Smith et al., 2022). This focuses on representing the experiences of individuals rather than generalising findings to the broader population (Smith et al., 2022). Participants were recruited who had experience with conversations about mortality and who were from one of three distinct groups (reflecting a purposive and homogeneity sampling structure):

1. Stakeholders within the death positivity movement,
2. Adults living with a life-shortening prognosis and,
3. Adults not living with a life-shortening prognosis.

The stakeholders were leaders and senior staff members from death-positivity organisations/groups such as Order of a Good Death, Death Café, Dying Matters, Public Health Palliative Care Movement, Charity organisations supporting people with life-shortening conditions and Hospice representatives. Individuals were recruited from these stakeholder organisations. The inclusion and exclusion criteria for the study are presented in Table 4.4 and were defined before recruitment to meet the study's aims and objectives.

Table 4.4

Inclusion/exclusion criteria for participation

Sample	Inclusion criteria	Exclusion criteria
Stakeholders	• Directly involved in death and dying conversation, supports/involved in death positive activities. • Have the capacity to self-consent. • Able to communicate via email and have access to the internet/smartphone technology.	• Not involved in death and dying conversations. • Does not support/involved in death positive activities
Living & not living with a life-shortening illness	• Must be over the age of 18. • Can speak and read English/work with a carer to do so. • Has the capacity to self-consent. • Be able to communicate via email and have access to the internet/smartphone technology.	• Any person under the age of 18 years. • Any person considered too ill to participate at the time of the interview for reasons of fatigue or physical/cognitive impact of treatments/condition.

Sample sizes in qualitative research are typically small due to the detailed nature of the data collection and analysis processes (Gray, 2014; Sandelowski, 1997). As outlined in Chapter 3, section 3.2, qualitative research focuses on exploring complex phenomena in depth and involves rich, detailed data collection methods such as interviews. Therefore, sample sizes are typically small to achieve depth rather than breadth in understanding the research topic. Researchers need to prioritise the quality and richness of the data over the participant numbers. Research can uncover nuanced patterns, themes, and insights within the data by engaging with rich data obtained from a purposeful sample. This intensive analysis allows a deep exploration of the participant’s prospects and experiences. Unlike quantitative studies, it is not always possible or desirable to predict precise sample sizes at the start of a qualitative study (Smith et al., 2022). However, it was essential to have sufficient participants to capture a diverse range of lived experiences of death and dying conversations. Determining sample sizes in qualitative research involves subjective judgment and experience (Sandelowski, 1997; Morse, 2000; Moser & Korstjens, 2018). Therefore, it was recognised that there would be a need for flexibility, increasing or decreasing the number of interviews/focus groups as the study progressed. Predefining sample sizes during the study design phase can be limiting as it will not facilitate adjustments in recruitment strategies essential to the iterative nature of qualitative research, where data collection and analysis occur concurrently. Therefore, for novice researchers, the guidance of experienced supervisors in sampling is crucial. Data depth, the themes being created, and practical considerations such as the timing and recruitment influenced the decision to stop recruiting participants. Assessing whether research aims have been achieved with the current sample size is a gradual process that evolves as the study progresses.

In qualitative research, the focus is on the quality rather than the quantity of data, aiming to provide a comprehensive understanding of individual experiences. Smith et al. (2022) suggest sample sizes ranging from three to twelve participants for doctoral studies working with interpretive phenomenology, emphasising the importance of flexibility over rigid numerical guidelines. A balance of participant numbers and available resources must be achieved to obtain sufficient in-depth and breadth data. Recruitment processes were attuned to the data collection methods, detailed in Section 4.6, following a discussion of the methods adopted.

4.5 Data collection methods

Data collection, in broad terms, refers to the systematic and structured gathering of information and/or taking measures that will answer the research question. Primary data can be collected from various sources, such as surveys and questionnaires, measurements, interviews, focus groups, and observations (Moser & Korstjens, 2018). Focus groups and interviews are widely established and appropriate collection methods in qualitative research due to their effectiveness in gathering information-rich data (Moser & Korstjens, 2018; Forrester, 2010). Focus groups generate discussion and debate and are useful for exploring complex/sensitive issues. While it is an efficient way of collecting vast amounts of data, facilitators must account for group dynamics and peer influence (Krueger & Casey, 2014). The interview is the most widely used data collection method in qualitative research. It is a social encounter where meaning is constructed through participant-researcher interactions to generate new knowledge (Krueger & Casey, 2014). Consequently, interviews enable in-depth exploration of the topic, are flexible, allow for personal connection, clarification in a confidential space, and individual focus. For this study, the chosen data collection methods were focus groups for the stakeholders and interviews with people living/not living with a life-shortening illness. Data collection, due to Covid restrictions, was undertaken online using Zoom.

4.5.1 Collecting qualitative data online

Online research methods use digital tools, platforms and technologies to conduct research and collect data. The COVID pandemic caused researchers to rethink the process of collecting data due to the restrictions imposed on social contact (Khan & MacEachen, 2022; Pocock et al., 2021), and this was the case in this study. Consideration had to be given to participants having access to adequate devices and software (Namey et al., 2022). Due to the COVID-19 pandemic's impact on social distancing, people learnt to work remotely and study online. As such, individuals became more proficient in using this technology to undertake work-related activities such as meetings, teachings and presentations. Typically, in face-to-face interviews, a private setting is chosen. However, in video interviews, if others are nearby, they may inadvertently observe or overhear the conversation. While this can be a concern in a home environment, it becomes more challenging when participants opt for public locations (e.g. undertaking interviews via smartphone in a coffee shop or restaurant). However, a potential benefit of online interviews is that they offer flexibility at a time and place that suits the participants best (Pocock et al., 2021). Death and dying is a sensitive topic, and as such, participants may become emotional or distressed; offering comfort may be more challenging online. Thunberg and Arnell (2021) suggest that, if undertaken thoughtfully, virtual interviews can empower participants by allowing them to end their participation abruptly and at any point. While participants can also discontinue in-person interviews, the simplicity of clicking a button makes it easier for a respondent to exit an online interview compared to excusing themselves from a face-to-face interaction. Details of the procedure are discussed below in sections 4.6.1 and 4.6.2

This study used the University of Leeds virtual conference system Zoom to conduct all the interviews. This enabled participants to join the interviews remotely and from a space of their choice.

4.5.2 The use of focus groups

Focus groups are a qualitative research method involving small groups of participants discussing a specific topic or issue under the guidance of a moderator/ facilitator (Braun & Clarke, 2013; Moser & Korstjens, 2018; Hennink et al., 2020). Focus groups allow for rich and in-depth debates through guided group interaction and discussions. They stimulate idea generation and uncover shared experiences and divergent viewpoints. They are effective for exploring complex or sensitive topics that benefit from group deliberation and interaction to elicit nuanced responses and diverse perspectives (Kornbluh, 2023). Undertaking focus groups with multiple participants simultaneously can be more time-efficient than individual interviews, enabling the researchers to gather data from several participants in a single session. However, focus groups can have some limitations, as there is potential for power differentials and dominant personalities to take over the group discussions. This was addressed using a moderator who oversaw the focus group.

Group settings can facilitate peer influence, encouraging participants to express opinions, share experiences, and engage in collaborative sense-making, leading to a richer understanding of the research topic. A focus group typically comprises 6 to 12 participants (Braun & Clarke, 2013; Moser & Korstjens, 2018; Hennink et al., 2020). This size can allow for a diverse range of opinions and perspectives while still being manageable for effective discussion and facilitation. Having too few participants may limit the variety of insights, while having too many can make it challenging to ensure everyone has a chance to contribute meaningfully to the discussion (Braun & Clarke, 2013; Moser & Korstjens, 2018; Hennink et al., 2020).

Focus groups were chosen for the stakeholder data collection. They provided a platform to include people from different areas of the death positivity movement. Participants shared their experiences and knowledge of working within organisations that support an openness toward death and dying. Based on the review findings outlined in Section 4.5.3, an interview guide was created for the focus group.

4.5.3 Individual interviews

Interviews are the most used data collection method for gathering in-depth information and insights, allowing researchers to gather rich insights from an individual on the chosen research topic (Braun & Clarke, 2013; Moser & Korstjens, 2018; Forrester, 2010). While interviews are commonly used within phenomenological studies, other methods, such as diaries and personal accounts, can be employed. Interviews were chosen because they offer a personalised approach to data collection, whether structured, semi-structured, or unstructured. By engaging in dialogue and probing for detailed responses, interviews facilitate the collection of detailed and nuanced data exploring participants’ beliefs, perspectives, and viewpoints of lived experiences. Interviews are particularly suited for this study as they allow for the co-construction of meaning between the participant and the researcher, with the interpretation being a blend of the two perspectives (Braun & Clarke, 2013; Moser & Korstjens, 2018; Hennink et al., 2020; Knott et al., 2022).

Interviews provide the flexibility to adapt to the answers given by participants to respond with follow-up questions, clarification, and exploration of topics. An active interview involves a guided yet flexible conversation where both the researcher and participant know the purpose and roles in the process (Holstein & Gubrium, 1995). The interviewer should consciously avoid dominating the conversation and let participants share their stories and reflections freely. The interviewer's skills, including cultural awareness and creating a mutual interest in the subject, are crucial for successful active interviewing (Roulston et al., 2003). Power imbalances in the researcher-participant relationship should be considered to maintain a dynamic interview setting (King & Horrocks, 2010; King et al., 2019), enabling participants to share their stories and experiences. The strengths of interviewing as a data collection method include obtaining a detailed and rich account of participants' perspectives, experiences, and motivations, as well as flexibility as interviewers can adapt questions and seek clarification and further information based on responses (Braun & Clarke, 2013; Moser & Korstjens, 2018). However, there have been several critiques of the interview approach. One limitation is regarding the robustness of using interviews as the sole method for data collection. This critique questions the depth and reliability of the information obtained, suggesting that this method may not capture the full complexity of the phenomena, such as the critique of the robustness of using interviews as a data collection method (Seidman, 1998; Sapsford & Jupp, 2006). Research bias can occur both during data collection and during the interpretation of the data, and the skills of the interviewer and the reconstruction of the experiences by the participants must be transparent (van Manen, 1998b; van Manen, 2016). Interviews can be viewed as a continuum, with semi-structured interviews being approximately equidistant between structured and unstructured interviews. When eliciting information from the participant, research bias is less likely in semi-structured compared to unstructured interviews because of the use of a topic guide – often influenced by existent evidence in the field/theoretical frameworks. For this study, semi-structured interviewing was chosen because of the interpretive phenomenological approach – to provide focus to discussion and prompts but also acknowledge the current evidence base linked to the research aims and objectives. Semi-structured interviews combine the flexibility of open-ended questions with a predetermined list of topics to explore and adapt questions based on the participants' responses. The interview guide is outlined below in Section 4.5.4.

Semi-structured interviews are conversational, which helps build rapport with the participants, encouraging them to share their stories, feelings, thoughts, and perspectives on death and dying conversations (Forrester,2010; Braun & Clarke, 2013; Smith et al., 2022). While there is flexibility, this interviewing structure ensures consistency across all the interviews, making it easier to compare and analyse the data whilst allowing for individual variations in responses. As in all research, ethical standards during a semi-structured interview must be upheld, including informed consent, maintaining confidentiality, and respecting the participants' autonomy and privacy (Forrester,2010; Braun & Clarke, 2013; Smith et al., 2022). Ethical considerations are outlined in Section 4.10.

4.5.4 Interview guide

An interview guide can be a structured outline or list of questions and topics used by the interviewer to guide the conversation during the interview. The guide can serve as a roadmap to ensure the key areas are covered and help maintain focus and consistency across the interviews. Guides typically involve open-ended questions and prompts to elicit detailed participant responses. The guide should also be flexible to allow for spontaneous exploration of new topics while addressing the primary research aims (Naz et al., 2022).

The study's overarching aim was to explore individuals' lived experiences of conversations about death and dying. It is a potentially sensitive topic; therefore, the type of questions and how they would be best framed required thoughtful consideration. A set of open-ended questions aligned with the aim was created, along with prompts to elicit detailed responses and encourage participants to share their experiences and perspectives. The questions had to be in a logical flow to ensure a smooth conversation, allowing for a natural progression from one topic to another. Questions were framed respectfully and non-threateningly to support participant comfort. The topic guides were reviewed with my supervisors, who provided additional insights and suggestions for improvement.

The interviews started with a less emotive opening question about what they did and how long (see Appendix 4). Participants were then asked to reflect on their experiences of what conversations they had about death and dying. Prompts and probes assisted with delving deeper into their thoughts, feelings, and interpretations. There was also flexibility with question phrasing and ordering, such as adapting the questions based on the responses received. This allows for new insights to emerge organically and capture the nuances of lived experiences and subjective perspectives. The interview guide was structured to elicit information about specific relationships in their lives and how these relationships influence their experiences, emotions, and perceptions. The nature of their interactions with others was also explored, and how they connect and relate to different individuals or groups. The questions were developed to allow participants to openly discuss their emotional responses within relationships, including feelings of intimacy, empathy, loss, or conflict, and consider the broader social, cultural, and environmental contexts concerning death and dying conversations. In addition, questions were aimed to elicit how participants construct meaning from their relational experiences, including their values, beliefs and discussions that shaped their understanding of death and dying. Participants were encouraged to explore experiences and how they make sense of these and their relationships with others and the world around them to uncover the intricate ways in which they perceive, engage with, and derive meaning. The interview guide was structured to achieve meaningful insights into the complexities of human connection and interaction and related lived experiences and perspectives of death and dying conversations. The interview guides are presented in Appendix 4.

4.6 Recruitment

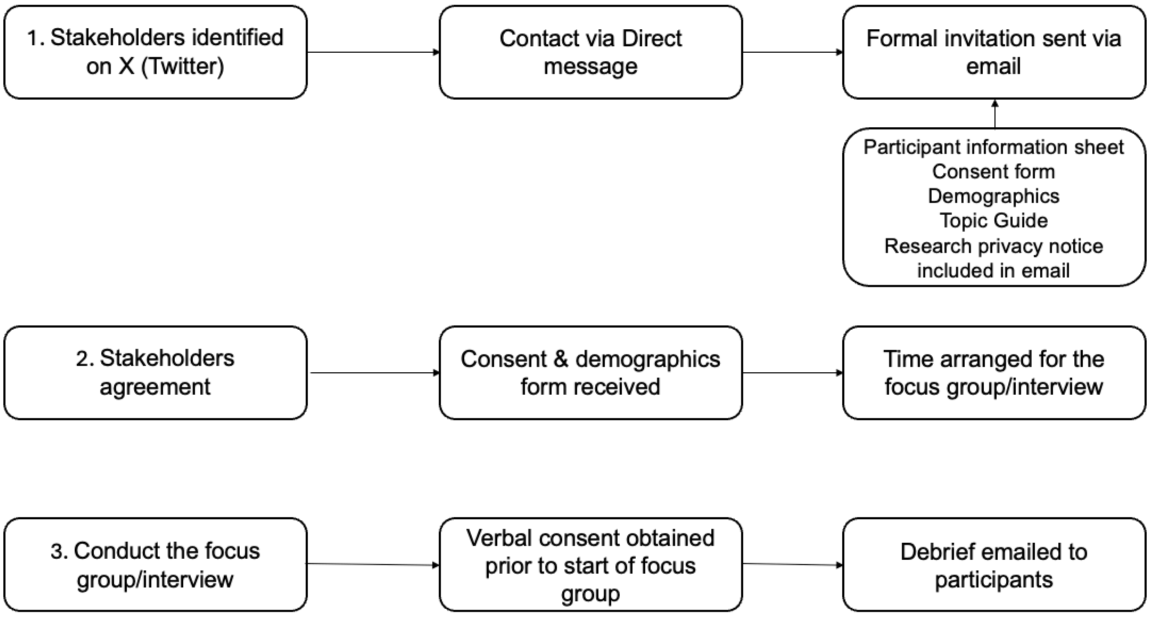
Recruitment in qualitative research refers to identifying, selecting, and inviting participants to participate in a study. This involves inviting individuals who have met the criteria outlined in Section 4.4 into the study. Several recruitment methods exist, such as direct contact, advertising, referrals, and using existing networks. An effective recruitment method is essential to ensure the study includes relevant participants who can provide valuable insights and perspectives on the researched phenomena (Forrester,2010; Braun & Clarke, 2013; Smith et al., 2022). Focus groups and interviews will be discussed separately, providing the information required to recruit the different participant groups.

4.6.1 Focus groups

Many stakeholders were active on X, a social media platform formerly known as Twitter). Figure 4.6.1 offers a visual presentation of the recruitment process. Stakeholder participants were contacted directly (via private message function on social media platforms) to open a dialect (see Appendix 5) and ask if they would be willing to participate in the study. Follow-up was made via formal university email (see Appendix 6) with an invitation to participate in the study, enclosing study information and related ethics documentation such as the participant information sheet (see 4.9.2 for the development of this document), consent form, demographics form (see Appendices 7-9), research participant privacy notice (see Appendix 10) and interview guide (see Appendix 4). Zoom instructions were provided if requested (see Appendix 11).

Figure 4.6.1

The process of recruitment, consent and data collection for focus groups



Focus groups of about six participants were envisaged to allow for in-depth insights into the stakeholders' experiences and perceptions (Plummer-D'Amato, 2008). Four participants were recruited, two from America and two from the UK. The focus group lasted for approximately one hour. Difficulty agreeing on a convenient time and date resulted in a decision to collect subsequent data from stakeholders through individual interviews. Therefore, an amendment was made to the ethics, allowing interviews with some participants individually (see Section 4.6.2). Seven stakeholders were interviewed, which lasted between 43 minutes and just over one hour.

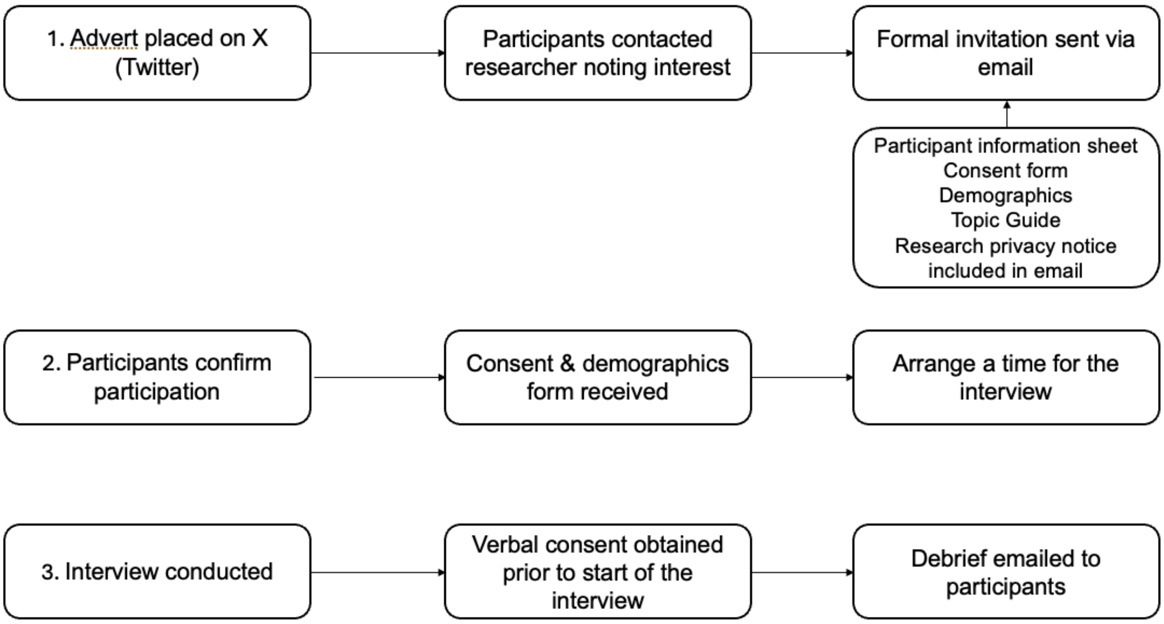
At the start of the focus group, the participants were reminded that any data used would be anonymised to protect their identity, and verbally requested their consent and confirmation that they agreed to be audio and video recorded. Participants were also asked to appreciate the confidential nature of the discussion for each other and to maintain everyone's anonymity. The focus group commenced with introductions and a sharing of experience in terms of professional roles and their relatedness to death and dying conversations. Several techniques are used, such as soliciting diverse perspectives, actively listening, and pausing (Kornbluh, 2023). When used and combined with the focus group agenda, it enhances the quality of the responses elicited. Allowances were made for silences and thought time to allow participants to reflect on the questions asked and time for them to digest information provided by the other participants. Clarification was sought when there were uncertainties about responses, and encouragement was offered by acknowledging participants' experiences; at times, this was non-verbal, with eye contact and a nod of the head. Probing questions were used to explore issues further where needed. Observing non-verbal cues via Zoom was more challenging than in-person focus groups to capture the dynamics of interactions. At the end of the focus group, participants were thanked for their time and emailed the debrief form (see Appendix 12), signposting them to various websites if they needed help/support following our discussion and due to the nature of the topic.

4.6.2 Individual interviews

As noted in the previous section, some participants initially selected to be recruited to a focus group discussion were subsequently invited to participate in an interview. Following the ethical changes allowing direct contact with individuals, adverts were placed on social media sites such as X (Twitter) and LinkedIn within the death positivity movement. When individuals contacted me interested in participating, a formal invitation was sent (see Appendix 13). Attached to the email were the participant information sheet, consent form, demographic form (see Appendices 7-9), interview guide (see Appendix 4) and the research privacy notice (see Appendix 10). Once the signed consent form was received, a mutually convenient time was arranged for the interview. Zoom instructions were provided if requested (see Appendix 11). See Figure 4.6.2 for a visual presentation of the recruitment process.

Figure 4.6.2

The process of recruitment, consent and data collection for individual interviews



Semi-structured interviews were undertaken with both adults with and without life-shortening conditions. Recruitment began via Death Positivity movement groups as they acted as gatekeepers. Permission was requested to advertise via their organisations to recruit individuals who have participated in their events for the individual interviews. However, following no response from the stakeholders, an ethics amendment was approved to advertise the study via social media platforms such as X and LinkedIn so potential participants could contact me directly (see Appendix 14). When individuals contacted me expressing an interest in participating, a formal e-mail invitation was sent (see Appendix 13). Attached to the email were the participant information sheet, consent form (see Appendices 15-16), demographic form (see Appendix 9), topic guide (see Appendix 4), and the research privacy notice (see Appendix 10). Once the signed consent form was received, a mutually convenient time was arranged for the interview. Zoom instructions were provided if requested (see Appendix 11). Seven participants were recruited for the group of individuals not living with a life-shortening condition, and the interviews lasted between 31 minutes and one hour and seven minutes. Seven participants were recruited for the group of individuals living with a life-shortening condition, and the interviews lasted between twenty-eight minutes and one hour and eight minutes.

At the start of each interview, I introduced myself. I explained the purpose of the interview, sharing my background details and interest in the topic area to build rapport and create a comfortable environment. Participants were reminded that any data used would be anonymised to protect their identity, and verbally requested their consent and confirmation that they agreed to be audio and video recorded.

The interview guide was memorised, making the interview more conversational. Rapport was built by listening actively, showing interest, and probing for more information when needed. Participants were asked to clarify any responses and asked for examples or details to explore further what they shared and to elicit details around lived experiences. I was mindful of paying attention to body language, but this was challenging over Zoom as it usually only had faces visible. However, attention was paid to the tone and pitch of participants' voices and facial expressions. At times, some participants were emotional, and time had to be taken to allow them to decide whether to continue (see section 4.9.2 for distress protocol information – no participants requested for an interview to stop). At the end of the interviews, participants were thanked for their time, and the debrief form (see Appendix 17) was emailed to them, signposting them to various supportive and charitable websites if they needed help due to the nature of the topic. All participants within the group living with/not living with a life-shortening illness were sent £20 Amazon e-vouchers as a token of gratitude for taking time out of their lives to be part of this research.

4.7 Data Analysis

Qualitative data analysis is inductive and focuses on understanding and describing participants' accounts and meanings. While a range of analytical methods are available, they are diverse and have different purposes and ontological and epistemological underpinnings. Broadly analytical processes can be grouped into 1) Quasi-statistical approaches, such as content analysis; 2) Frameworks or matrices, such as thematic analysis; 3) Interpretative approaches, such as interpretative phenomenological analysis (IPA) and grounded theory; 4) Socio-linguistic approaches, such as discourse analysis and conversation analysis (Smith et al., 2011; 2011a). However, there is a common set of principles across methods: transcribing the interviews, immersion in the data to gain detailed insights into participants’ accounts, developing a coding system, and linking codes together to form overarching categories/themes (Forrester, 2010; Braun & Clarke, 2013).

Analytical methods like the framework approach (Spencer et al., 2003), thematic networks (Attride-Stirling, 2001), and Reflexive Thematic Analysis (RTA) (Braun & Clarke, 2022) are becoming popular because they offer a set of linked stages that help navigate the process of analysis. These methods can provide rich insights into complex phenomena, such as conversations about death and dying, and be applied across a range of theoretical and epistemological approaches (Spencer et al., 2003; Braun and Clark, 2006). RTA was chosen as an analytical method because it enhances interpretive phenomenology by offering a structured approach to recognise and examine themes within subjective experiences (Braun & Clarke, 2022). It aligns with the philosophy of interpretive phenomenology by focusing on understandings and meanings through interpretation. RTA emphasises flexibility, consistency, and detailed reflection in the coding process to ensure a comprehensive data analysis. It also examines and reveals the researcher’s involvement in generating knowledge.

Thematic analysis (Braun and Clarke, 2006) has faced criticism for lacking depth, fragmenting data, being subjective, and lacking transparency in theme development. This can make it challenging to assess the robustness of the results (Attride-Stirling, 2001). In contrast, RTA (Braun & Clarke, 2022) addresses these concerns as the approach emphasises reflecting on the researcher’s interpretations and assumptions throughout the analysis process. RTA involves systematically identifying patterns and themes in the data while considering the researcher’s reflexivity, subjectivity, and positionality. This method encourages critical engagement with the researcher’s perspectives and biases to ensure a more nuanced and transparent data analysis. RTA is beneficial in exploring complex or sensitive subjects, such as conversations about death and dying. It allows the researcher’s reflexivity to play a significant role in shaping the analysis and interpretations of findings.

Braun & Clarke’s (2022) RTA framework, consisting of six interlinked phases, underpinned the data analysis. However, I also drew on the philosophical and methodological underpinnings presented in Chapter 3. This allowed me the flexibility to stay as close to the data as possible. Braun & Clarke (2020) advocate for researchers to clearly state their philosophical beliefs and theoretical foundations and maintain a consistent, coherent, and transparent approach, not adhering to procedures but rather engaging thoughtfully and reflexively with the data and the research process. Using RTA makes it possible to uncover latent meanings and make the interpretive process transparent (Levitt et al., 2016). As seen in Finlay & Payman's (2013) research exploring the lived experience of traumatic abortions and Finlay's (2015) regarding the experience of entrapped grief following a traumatic abortion, RTA can be adapted to the different phenomenological theoretical frameworks. This flexibility and strength make RTA suitable to be integrated into the analysis endeavour (Finlay, 2021).

The six phases of RTA are 1) Familiarisation of the dataset; 2) Coding; 3) Generating initial themes; 4) Developing and reviewing themes; 5) Refining, defining and naming themes; and 6) Writing up the analysis. These phases, as suggested by Braun and Clarke (2022), are interconnected and it is not a requirement to follow the stages in a linear progression. This process allows for developing themes as iterative by revisiting, exploring and being in tune with nuances beyond the apparent content and meaning.

Throughout the analysis process, hermeneutical reflexivity was incorporated into the data collection and analysis approach. I was cognizant that my investigation of the phenomena in both the focus groups and individual interviews required the recall of experiences and for these experiences to be relived in my company as the researcher. Therefore, this intersubjective relationship needs to be recognised. Interpretation is crucial to extracting meaning and understanding from shared perceptions and experiences. In this context, understanding and ‘meaning’ are viewed as created in part via my preconceptions, frames of reference or world views and expectations (Finlay, 2003). Therefore, the interpretation results arrived from a fusion of horizons – the meeting of my own and my participant's experiences (Gadamer, 2004). To appreciate this reflexive methodology, journaling was used. This helped me to consider in what ways my preconceptions as a psychologist with experience of close family member bereavement and a supporter of the death positivity movement might affect both the undertaking of data collection and analysis (Finlay, 2003). To this end, the reflexive account considered the relational experience in illuminating the phenomena in question and drawing on different constructs recognised within the interpretive phenomenological approach. To allow readers to enter this shared world of understanding, I drew on the different lifeworld existentials (van Manen, 2016) and, at other times, engaged in imaginative dwelling and horizontalisation to reach some adequate description, interpretation and understanding of how death and dying conversations are lived.

Engagement with the hermeneutic circle supported my mindfulness towards the analysis, from initially reading the transcripts to identifying the participants' main ideas, emotions and perspectives. There were times when the individual parts of the conversation/interview/focus group transcript alluded to personal experiences, cultural references, or analogies/metaphors. To gain a deeper understanding of the nuances and meanings embedded within the conversations, an appreciation of these parts within and across participants contributes to the overall understanding and how the overall understanding influences the interpretation of the individual parts and related meaning-making. This back-and-forth process helped refine and deepen my understanding of people's conversations about death and dying. This process is repeated and revisited, and the interpretation is adjusted based on any new insights gained to arrive at what feels to be a comfortable or accessible interpretation. Using this hermeneutic circle approach to the data enables a comprehensive and nuanced understanding of complex and sensitive phenomena such as death and dying conversations.

In addition, imaginative dwelling allows a personal exploration of the various aspects of the death and dying conversations, helping to understand the participants’ thoughts, feelings, and motivations to uncover deeper meanings and insights, paying close attention to any metaphors, analogies, or symbolic language used to describe death and dying and using my own experiences to interpret these symbols allowed for a deeper understanding of underlying meanings and beliefs. Reflection was also undertaken on the emotional impact of the conversations and considered how the participants shaped their perspectives and reactions to death and dying. At the same time, I explored my emotional responses as they provided valuable insights into the themes created and the dynamics of the death and dying conversations. In addition, consideration was given to how societal norms, religious beliefs, or cultural practices can influence the participants’ perspectives on death and dying, which may shed light on any underlying factors that shape their conversations about death and dying and the experiences of those conversations. Employing imaginative dwelling, it was hoped to gain a deeper appreciation of the personal, social, and cultural constructs involved in experiencing the phenomena. This phenomenological technique provided a more empathetic and nuanced understanding of the complexities surrounding death and dying conversations.

Finally, horizontalisation was used within this study. I approached the topic of conversations of death and dying with an open mind and a willingness to explore different perspectives. To engage in a direct and non-judgmental exploration of the conversation, listening attentively to participants' viewpoints, experiences, and emotions regarding their discussions about death and dying without imposing judgments or evaluations. The aim was to focus on the participants' words, tone, and non-verbal cues to better understand their conversations about death and dying. Trying to put myself in their shoes and imagine how they might be feeling or what they might be going through. Consideration was given to any underlying meanings, assumptions and values embedded in these conversions. Patterns and themes were considered, and any contradictions that may develop from the analysis (described in the next chapter). By employing horizontalisation in the analysis of people's conversations about death and dying, the topic was approached with openness, allowing for a more accurate or adequate and nuanced understanding of the diverse perspectives and experiences people have regarding death and dying.

4.7.1 Familiarising with the data

The first phase of analysis involved familiarisation of the data. To do this, I listened to the recording, read and re-read the transcript, and made notes on anything that caught my attention or could be seen as important to the participant’s story. This part of the process allowed me to pick up any nuances that may have been missed during the interview. I actively challenged and asked myself deeper questions about the data, identifying some possible patterns and deeper meanings of the text.

4.7.2 Coding

This process involved engaging with the hermeneutic circle. While reading the transcripts, participants' ideas and emotions were identified along with their different perspectives. I delved deeper into the transcripts as the participants discussed more personal experiences to understand better the nuances and meanings embedded in the conversations. This process was repeated, and any interpretations of new insights were gained. This back-and-forth process is congruent with Braun & Clarke’s suggestion that RTA is not linear.

Imaginative dwelling was also utilised during the coding process, using imagination to recreate and explore the various experiences told by the participant. This resulted in exploring the different aspects of the death and dying conversations to understand perceptions, uncover any deeper meanings or insight and pay attention to the analogies or symbolic language to gain a deeper understanding of the meanings and beliefs of the participants and their lived experiences. Consideration was given regarding how societal norms and religious beliefs influenced the participants’ death and dying conversations.

Horizontalisation was also employed throughout the coding process. Being immersed in the data required consciousness in a non-judgmental way. I listened to the participants' perspectives and tried to put myself in their shoes. By utilising the hermeneutic circle, imaginative dwelling and horizontalisation, there was the development of a comprehensive understanding of the complex and sensitive topic of death and dying and an empathetic understanding of the complexities and nuanced understanding of people's diverse perspectives and experiences regarding the phenomenon.

Systematically working through the data set, starting with the stakeholder group, then the life-shortening illness group and finally, the group of adults living without life-shortening conditions. Using the analysis software Quirkos (Quirkos, 2024) was intuitive and aligned with my way of thinking. For example, seeing the codes in a visual representation made phases 4 and 5 manageable. Meaningful codes were applied to the transcript texts, capturing the data's explicit, surface, conceptual and implicit meanings. Appendix 18 provides an example of a Quirkos output linked to this stage of the analytic process.

4.7.3 Generating initial themes

van Manen (1997) describes a theme as a fundamental aspect of human experience created through phenomenological inquiry. A theme must represent a central idea, pattern or essence that can capture the underlying meaning or significance of the individual’s lived experience. van Manen emphasised the importance of identifying and exploring the themes in phenomenological research to uncover the deeper layers of human existence and consciousness. Themes also provide a framework for understanding and interpreting the complexities of subjective experiences, allowing me to delve into the richness and depth of lived experiences and the conversations people have about death and dying.

This phase of the analytical process involves identifying shared patterns and meanings across the data set. Codes were gathered that appeared to share a core idea or concept, which could provide meaning that would answer the research aims. This is an active process where themes were constructed based on my knowledge and insights, bearing in mind the study's research aims. Using interpretive hermeneutic phenomenology, an attempt was made to understand the participant’s lived experiences and how their social world had helped in some way to shape their experiences of death and dying conversations. This approach enabled me to view the cultural, social, and personal factors influencing their experience and understanding of conversations about mortality. Here, the themes described the broader shared meaning rather than the more specific codes.

4.7.4 Developing and reviewing themes

Within this phase, an assessment was made of the initial ‘fit ‘of the provisional themes and the viability of these themes. The themes were reviewed to make sure they made sense in relation to the coded extracts and the entire dataset. Consideration was given to how the themes related, ensuring I understood the meaning the participants were trying to convey. This iterative process was undertaken to ensure that a compelling story of the important patterns of shared meaning related to death and dying conversations was developed. Theme headings were changed as I took a step back to fully process the narrative being developed to ensure that the themes were staying close to and preserving the lived experiences of the death and dying conversations the participants were sharing.

At this stage of the process, member-checking the themes was considered. Member checking is regarded as the ‘Gold standard’ for quality and is a validation technique used in qualitative research where researchers present their findings or interpretations to the participants. This allows them to confirm the accuracy of themes and ensure that participant perspectives are accurately represented (Lincoln & Guba, 1985; Creswell & Miller, 2000). However, interpretive research aims not to prove or make broad statements but to understand the core of lived experiences. This makes the idea of validation appear somewhat unreasonable. Member-checking focuses on identifying when the most appropriate interpretation has surfaced where certainty is not highly valued in the interpretative context (McConnell-Henry et al., 2011). Due to the interpretive aspect of this study, interpretations can differ depending on the perspective. In embracing Heidegger's ideas, which include acknowledging multiple truths, this makes member-checking incompatible with the philosophical position taken for study (Taylor, 1995). Recognising the importance of context, time, and space is essential in interpreting experiences (Heidegger, 2010). Heidegger suggests that truth in this context is subjective and can be shaped by factors like context, mood, or the attitudes of both the researcher and participant.

During qualitative analysis, as reflection, interpretation, and synthesis occur, creating second and third-level constructs of meaning can gradually move the findings away from the initial interview data (Grbich, 2013). Additionally, member checking faces complexities due to epistemological and methodological obstacles, like evolving understandings of phenomena, ethical concerns about sharing data with participants, the challenge of including dissenting perspectives, and deciding who bears the primary responsibility for interpretation (Birt et al., 2016). In addition, possible alterations in participants' social and health conditions could create difficulties in conducting follow-up contact due to practical constraints or ethical considerations (Taylor, 1995). This reinforces Heidegger's idea that the significance of time, space, and context in experiences is context-specific, making reinterviewing inconsequential outside the philosophical tradition (Whitehead, 2004).

4.7.5 Refining, defining and naming themes.

This stage involved fine-tuning the analysis, ensuring each theme was clear and built around a strong core concept. Throughout this process, questions were asked as to how the theme fits into the overall story. Brief bullet points were created that summed up each theme's content and made any alterations to the theme names. At this point, peer checking was used, where supervisors provided feedback to ensure accuracy and quality. The final aim is to produce strong and rich text by creatively presenting the participants' voices and their lived experiences of the death and dying conversations they had. Refer to Appendix 23 for an example of theme identification and analytical processes.

4.7.6 Writing the analysis

The final phase of 'writing the analysis' involved weaving the analysis with vivid data extracts to provide a coherent and rich interpretive story of the participants' lived experiences and the meanings they attach to the experiences of death and dying conversations. Writing is essential to hermeneutic interpretation as it involves noticing and thinking about interesting things (van Manen, 1997, 2016). No schema could be drawn upon to help with this process when beginning to write. As an interpretive inquirer, I needed to ensure that the writings of my interpretation of the participants' experiences represented their voices and could be readily conveyed to readers.

How the text speaks and affects our understanding forms meanings important to interpretive hermeneutic phenomenological research. Writing the analysis involves the incorporation of lived thoroughness, evocativeness, intensity, tone, and epiphany (van Manen, 1997).

Lived thoroughness describes a person's experiences and events as part of life, shaping their perspective and understanding of the world. It acknowledges the impact of personal experiences on an individual's beliefs, values, and behaviours. The phenomenon is placed concretely into the lifeworld so the reader may experientially recognise it. The aim is to portray the phenomenon so that, as the reader, you may find continuity between the portrayal of the phenomenon and the particulars of your own life. In the following chapters, I discuss the experiences of the conversations of death and dying and their impact on life. Readers may recognise these experiences and find a link d between the text read and their own person's experiences of death and dying conversations. According to van Manen (1997), a concrete portrayal of text can place the reader in the midst of lived reality. Therefore, continuity can be initiated between the interpreted text and thus recognise the particulars of one's own life.

Evocation refers to bringing thoughts, emotions, feelings, or memories to the forefront of one's mind, often in response to a stimulus or trigger. It involves recalling or summoning specific mental content from memory or the subconscious. This can be a deliberate or spontaneous mental process and brings the experience into the present to reflect on it phenomenologically. For example, in the following chapters, there are descriptions of people's conversations on death and dying that can be recognised. Here, the challenge is to produce writing that provides a concrete description and evokes vivid images and associates that prompt our thoughtful reflection.

Tone allows the text to speak to us and to bring out the inner meaning within the phenomenological text through the interpretive process. We read a text or see something, but in addition to this visual experience, we recognise something deeper through an auditory sense. This tonal meaning is acquired from being sensitive to the text beyond its informational value by focusing on the expressive qualities within and the context surrounding the text. How one regards something, however, is only sometimes accurate. The following chapters aim to create and imagine for the reader the forms of being as a signification of humanness by providing examples to illustrate meaning, which may involve a degree of imaginative variation.

Epiphany is the sudden realisation, insight, or comprehension that leads to a moment of sudden revelation or insight experienced by the reader. It often leads to a deeper understanding or significant realisation. It is a transformative effect so that the more profound meaning makes an edifying appearance to the reader's self, such that it can provide a sudden perception of the life meaning of something, so substantial that it may stir us at the core of our being. I hope that the text of the findings and the whole of the thesis will reveal itself to be rich, diverse, pertinent, and of significant quality for the readers, which validates their experience, stirs sensibilities, and makes them think. Ultimately, the readers will decide whether I have achieved this.

4.8 Ensuring quality and rigour of the study

To maintain rigour in this interpretive phenomenological study, I, as the researcher, must enter the world of others and also bring you, as the reader, into this world. To do this, the research questions, methods, data collection and analysis procedures, and findings must be clearly articulated and transparently explained. This information has been outlined in previous sections.

Qualitative research faces scepticism due to the influence of principles like generalisability, validity, and reliability borrowed from quantitative research. It is crucial to demonstrate the significance of scholarly work that can answer the question, ‘so what?’ (Sendelowski, 1997). The most used framework to assess the rigour of qualitative research is that of Lincoln and Guba (1985), which has four processes:

1. Credibility: This uses different data sources, member checks, and debriefing peers.
2. Transferability: This is done by providing detailed descriptions of the research context, participants, methods, and philosophical underpinnings that allow readers to assess the findings' transferability to other settings.
3. Dependability: This is done by maintaining clear and detailed documentation of the research process, including an audit trail that outlines decisions made throughout the study.
4. Confirmability: acknowledging research bias through reflexivity and peer review.

The research process needs rigour, which details the justification of the methodological choices made, along with reflections on how the study findings may be transferable to other contexts or populations. In addition, the study needs to be situated within the existing literature to show how this research contributes to the current knowledge. Having opted not to rely on specific procedures or predefined criteria to guarantee quality, as these aspects are subject to extensive debate in the literature. Instead, I posit that a successful phenomenological study attains quality by emphasising the intricacy, uncertainty, and conflicting aspects of participants' experiences. Dahlberg et al. (2008) warn that phenomenological researchers should be mindful of avoiding definitive conclusions about what is inherently indefinite. Instead, lifeworld research should be recognised for its capacity to elucidate paradoxes, reconcile opposing viewpoints, and showcase holistic perspectives (Dahlberg et al., 2008).

Irrespective of the chosen research methodology, aligning it with the philosophical foundations underpinning the endorsed research tradition is crucial. In interpretive research, a deep understanding of the philosophical principles guiding the specific approach is essential, and consistent adherence to these principles is paramount. van Manen (1998b) emphasises the importance of researchers being able to articulate the theoretical and epistemological principles of phenomenology and hermeneutics. The use of consistent language in discussing the research work is critical as it signals the researcher's grasp of the epistemological connections supporting the chosen approach, thereby enhancing the scientific rigour of the study. In a Gadamerian context, scientific adequacy involves the skilful and deliberate application of interpretive techniques with a reflective process during text interpretation. This is pertinent in the current analysis, where themes are interpreted based on previous literature and existential perspectives. The interpretation should be deemed sufficient, satisfactory, and plausible. To ensure scientific adequacy, the language used to describe the research approach and the understanding of the phenomenon of interest must reflect this rigour (Watson & Girard, 2004). Meaning emerges from the context of the researcher-participant interaction, where understanding is constructed through iterative reading and interpretation (Gadamer, 2004).

Several processes were used in this study. An audit trail was created by outlining the decisions made throughout the process, providing a rationale for the chosen methods/methodology and interpretations. A reflexive journal was maintained to maintain credibility. By doing this, I note my self-awareness throughout the research process (see Appendix 19 for excerpts from my journal). It shows how my history and personal interests influenced my interpretations. The journal provided a rationale for the decisions made, noting any instincts and the challenges experienced during the research and providing transparency throughout. It also helped develop thoughts and ideas on the themes (See Appendix 19 for excerpts from my journal). I have also set out my phenomenology within Chapter 1, showing the reader my biases and background, again providing transparency. I also acknowledged the need for patience in analysing interpretive practices, accepting the presence of inconsistencies and differing explanations of emotions and events and ensuring that the writings reflected the complexity of social life to avoid overlooking crucial aspects of the data. This was done by offering detailed descriptions of the research methods, the context of the study, and data-rich information with data extracts included in the reporting of the findings, allowing the reader to make an informed decision regarding the transferability of experiences and interpretations to their specific contexts.

4.9 Ethics

This section includes ethical considerations related to the study topic, in that death and dying are considered sensitive. Ethics in terms of the ethical conduct of the study, such as informed consent, confidentiality, anonymity, data management, and the well-being of the participants and the researcher, are also addressed.

4.9.1 Undertaking sensitive research

Studying sensitive healthcare topics is important as it gives a voice to underrepresented groups in research. Neglecting research on sensitive issues or marginalised populations can restrict the evidence base, leading to gaps in understanding the needs of the individuals and communities served. This can result in certain areas of care lacking evidence-based practices, being ineffective, or failing to be inclusive (Pinto et al., 2021).

Building rapport with participants is essential in sensitive topic research to create a comfortable environment for sharing personal experiences. It is crucial to clarify consent, allow participants to control the conversation, and be prepared to handle distress if it arises during the session. A distress protocol (see Section 4.9.2) should be in place to guide researchers in managing participant distress without offering advice but providing appropriate support and resources when needed (Pinto et al., 2021). Researchers of sensitive topics must consider the emotional impact of listening to participants' traumatic experiences and recognise how personal experiences may affect their emotions. It is essential to take breaks between data collection sessions to process emotions, seek peer support, keep a journal for reflection, and ensure emotional well-being when dealing with challenging sessions (Pinto et al., 2021). Involvement with sensitive topics can open new thinking areas to help develop the evidence base. The following section discusses the ethical implications of this study.

4.9.2 Ethical approval

The University of Leeds School of Healthcare Research Ethics Committee (SHREC) granted ethical approval for the study and all documentation on 22nd October 2022 (see Appendix 20). A further amendment was requested and approved concerning the recruitment procedure. In addition, as a member of the British Psychological Society (BPS), the ethical code was strictly adhered to throughout the study. The Code of Ethics and Conduct is for all members of the society to guide day-to-day professional conduct (BPS, 2021).

Following the University of Leeds SHREC guidelines, participant documentation was developed, such as the participant information sheet and consent forms. Participant information sheets and topic guides were reviewed by the University of Leeds School of Healthcare Experts by Experience in Education & Research (SHEER) Group for dissemination (see Appendix 21 for meeting minutes). A meeting was attended, and the study was presented to the group. They provided valuable advice to ensure the documentation was easily understandable for the target sample. My recruitment plans and safety measures were also discussed to safeguard participants.

The study included a distress protocol and safeguarding procedure (see Appendix 22) to allow participants to change their minds at any point and, if desired, withdraw from the study. Details of supportive organisations were also given to all participants following the interviews.

4.9.3 Well-being of participants

Interviewing participants concerning their lived experiences on a sensitive topic can evoke many emotional responses. These responses must be handled so as not to harm the individual further. The participant information sheet and topic guide were submitted to the SHEER Group, and adjustments were made to ensure that individuals understood what they were asked. The feedback from the Group was crucial as it enabled the development of the documentation. For example, the Group mentioned that the original document was too long, four pages, and it allowed for the development of the document. Following the SHEER comments, the document was reduced to 3 pages.

It is also considered good practice to build a rapport with your participants that is culturally and developmentally appropriate, considering gender, socioeconomic status, culture, and religious contexts. This means offering breaks if the participant is showing signs of distress, giving participants the time to express their thoughts and emotions, and being prepared to end the interview if needed. A distress protocol was created for the study detailing the steps that could be taken (see Appendix 20).

4.9.4 Well-being of researcher

With any research, consideration is given to the participant’s well-being, which is considered the priority. However, care must be given to the researcher. Listening to participants talk about their lived experiences could be distressful, primarily as the topic covers death and dying, which is seen as a sensitive topic. Though many researchers want to collect their data quickly, it is prudent to take time between each interview to allow for processing any emotions the discussion may have evoked (Etherington, 2004). Writing in a journal reflecting on the feelings and reactions to the interviews will enable the researcher to explore these feelings further. Peer support sessions are also a valuable way to reflect. These methods allow the researcher to maintain balanced emotional well-being. In addition to these methods, the researcher should take breaks between sessions to process the information received and reflect on what was heard (Etherington, 2004). During this study, I sought support from my peers, close family and friends as I felt overwhelmed following the expected death of my mother.

4.9.5 Informed consent

Informed consent was obtained from each participant before the data collection. Participants were informed that the study was exploring people’s conversations regarding death and dying and would be asked several questions. The information sheet provided to each participant assured that their participation was voluntary and anonymous and that any material shared would remain confidential. Participants were also informed that they had the right to terminate their participation at any time, up to the point of analysis, without reason or consequence. The SHEER Group saw the informed consent document (see 4.9.2 for full details).

4.9.6 Maintaining anonymity and confidentiality

Participants were informed that their names would only appear on consent forms, kept separately from any interview transcripts, on a password-protected document. Participants were asked if they wished for their contact details to be kept so that the study results could be sent to them once completed. All participants were given a pseudonym, and all other identifiable information was edited/removed. Participants were informed that their data would be treated anonymously and confidentially and that they did not have to share anything they were uncomfortable sharing. Transcription was available immediately after each interview as the meeting took place via Zoom video conferencing system (Zoom, 2024). All transcriptions were depersonalised, and any of the participants' identifying information was replaced with an unrelated sequence of characters. Participants were asked to confirm they were happy to have transcript material quoted in the study results, but their real names would not be used unless requested. In addition, access to the data will be restricted to my supervisors and me.

4.9.7 Voluntary nature of participation

All participants were informed, in writing and reinforced verbally before the commencement of the interview and focus groups, that participation in the study was voluntary and that they had the right to withdraw without reason or consequence. If participants requested to have their data removed from the study following the interviews or focus group, they were given up to four weeks from the data collection, after which analysis commenced, and data removal would not be possible.

4.9.8 Limits to confidentiality

Participants were informed that the information provided would remain confidential unless they revealed something suggesting a risk of serious harm to themselves or another person. Such disclosures did not occur but would have been reported to the relevant authorities, such as social services or local safeguarding teams.

Due to the nature of a focus group, confidentiality could not be guaranteed. However, all steps were taken to maintain confidentiality, as previously highlighted in Section 4.9.6. Participants were reminded to respect the privacy of their fellow participants and not to repeat what was said within the focus group to others.

4.9.9 Data management and storage

Personal data such as names and contact information (needed to arrange interviews) were kept separately from participants' data. They were only held with the participant's permission on the M-Drive of the University of Leeds secure server. A record of participants' names and corresponding pseudonyms was kept in a password-protected file on the M-Drive of the University of Leeds secure server. Interview recordings were downloaded, deleted from Zoom, stored on the M-Drive of the University of Leeds secure server, and destroyed upon completion of the PhD. However, anonymised transcriptions will be kept for five years to allow for research publication. All data generated during the study will be retained per the University's Data Protection Policy and stored on the M-Drive of the University of Leeds secure server. Upon completion of the PhD will be destroyed. In addition, the guidelines relating to data management and storage in the General Data Protection Regulation (GDPR: GDPR, 2018) were adhered to throughout the study.

4.10 Summary

The choice of research design and methodology, using interpretative phenomenology, drawing on the work and methods of Findlay's Relational phenomenology and van Manen's lifeworld existentials, has provided a rationale and detail of the application of the methods used to understand individuals' conversations regarding death and dying. An explanation of the data collection, sample selection and analysis methods have been discussed. The importance of reflexivity, rigour, and ethical considerations have been deliberated, and I have highlighted how and in what ways I have drawn on key tenets of interpretive phenomenology.

My involvement as the researcher in the data implies that my interpretations may vary from those of another researcher. Phenomenology relies significantly on the researcher's personal engagement. Through careful consideration while interacting with participants, conducting interviews, reflecting on perspectives related to people's conversations about death and dying, and ensuring rigour and sufficiency, I have developed a capacity for reflection and mindfulness in my actions and interpretations.

The subsequent three chapters present the results from the stakeholders, individuals living with a life-shortening illness, and those without an illness.

Chapter 5
Stakeholder findings

5.1 Introduction

The findings from each of the three data sets (stakeholders, people living with a life-shortening illness, and those not living with a life-shortening illness) are presented in the following three chapters. Chapter 8 discusses the integration of some of these themes for the three participant groups, where the findings are critically evaluated in relation to the wider literature. This chapter provides a comprehensive overview of the findings from the stakeholder interviews, focus group data and subsequent analyses, from which key themes were identified. Insights into the stakeholders' perspectives, opinions, and experiences of death and dying conversations through a detailed presentation of participant extracts and relevant implications in relation to the broader research context are offered.

5.2 Methods summary

The focus group had four participants, all recruited via social media and X (formerly Twitter) posts. Data collection was conducted online, using procedures detailed in Chapter 4, section 4.6. The focus group lasted approximately one hour. Seven individual interviews were also conducted, and participants were again recruited from social media. Their interviews lasted between forty-three minutes and one hour and seven minutes. All interview participants resided in the UK; however, two participants resided in the USA.

Recruiting participants from both the USA and the UK had the potential to obtain valuable insights from diverse cultural perspectives and experiences. However, consideration was given to the cultural norms and values that influenced participants' responses from the UK and USA. Differences in language nuances and communication styles between USA and UK participants had the potential to impact data interpretation and analysis. They were considered during the analysis, as outlined in Chapter 4, Section 4.7 outlined. In contrast, the similarities between these cultures could also potentially limit the transferability of findings to other cultural contexts. In addition, they may not capture the full range of diversity within each country, which is a limit of the findings. Acknowledging these limitations is crucial to ensure the validity and reliability of the study findings. A brief outline of each participant is presented below:

Alison: resides in America and did not divulge her age at the time of the interview. She is a business owner who created tools and opportunities for people to learn about end-of-life, education and planning. Her business operates in several countries but not yet in the UK. Alison was a member of the focus group.

Stuart: resides in the UK and did not divulge his age at the time of the interview. He has spent many years working in the charity sector, particularly in social welfare and mental health. He currently works in hospice care because he perceived that NHS care for the dying was not good compared to the care given in a hospice. Stuart was a member of the focus group.

Dexter: At the time of the interview, Dexter was a 47-year-old American who had become an independent educator with Alison’s company. Before becoming a life coach, he had previously worked as a teacher and ran a tutoring company in New York. He grew up with a Presbyterian father in a household that discussed death and dying. Dexter was a member of the focus group.

Paul: resides in the UK and did not divulge his age. He has spent 30 years integrating holistic, person-centred, and compassionate care into nursing, midwifery, healthcare, and educational programmes. Paul is a professor of nursing who works for a university and NHS trust. He was a member of the focus group.

Stef: resides in the UK and was a 56 -year-old woman working for a hospice supporting people in the with the community. Her role involved breaking down the barriers that stop people from having death and dying conversations. She had a significant career change, as Steff worked in revenue and customs before this role. Stef sees death as part of life.

Angelica: resides in the UK and at the time of the interview, Angelica was a 49-year-old woman. She works as a hospice chaplain and is the hospice's spiritual care lead.

She had worked as a chaplain before joining the hospice team in a different setting, and before that had been a community nurse. She sees death as part of life.

Joseph: resides in the UK and was 64 years old at the time of the interview. He has worked in fundraising at other charities for most of his working life and now works at the Motor Neurone Disease Association. He feels death is part of life and that we should embrace it.

Steven: resides in the UK and did not declare his age at the time of the interview. He works at a hospice and found that being part of the hospice team changed the way he viewed death and dying. He is involved in improving the communication of the general public towards death and dying conversations.

Rebecca: resides in the UK, and at the time of the interview, Rebecca was a 69-year-old woman. She has a psychology background and is a transpersonal coach. She currently volunteers at a hospice. Her husband suffered from a brain tumour. She feels death is part of life, and we should live in the moment.

Dillen: Dillen resides in the UK and was 40 years old at the time of the interview. He works for the Motor Neurone Disease Association (MNDA), where his role includes supporting volunteers across branches, liaising with health and social care professionals, and providing education on MND. His mother’s death changed his perspective on death and dying and helped normalise the subject. He feels people should be open to having conversations about death and dying.

Stella: resides in the UK and at the time of the interview, Stella was a 45-year-old woman. She works for the MNDA as a community fundraiser. She had considered becoming a teacher, but she did feel the role would not suit her, and she has worked with the MNDA for the last 16 years. She feels her role is a privilege because she talks to those living with MND as well as their family members. She had a Christian upbringing, which she felt made accepting death and dying easier, but she does not currently subscribe to any particular religion. She believes we are energy and that this goes back into the cycle of life when we die.

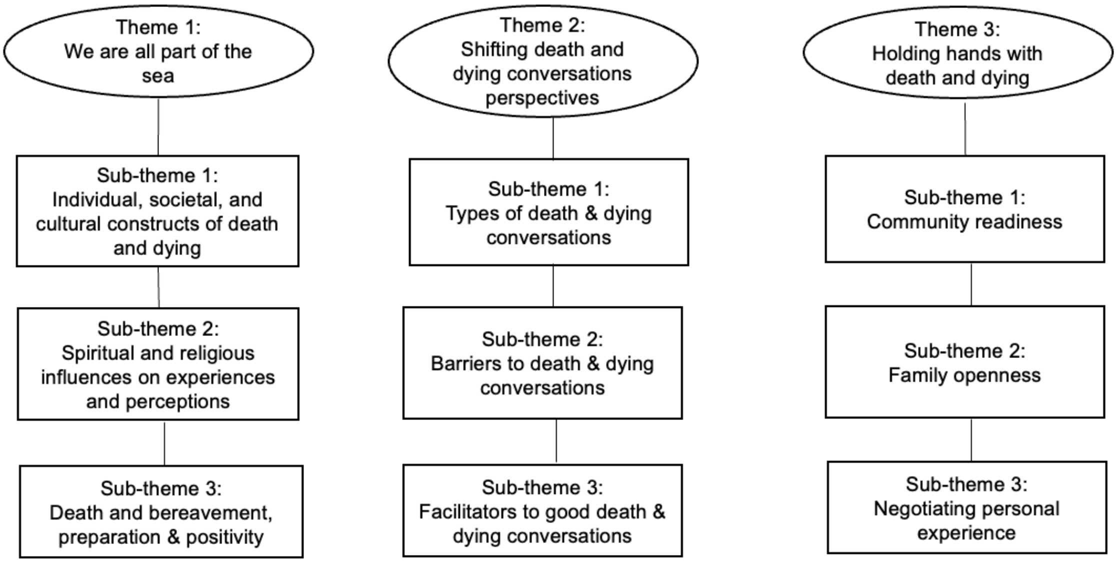
5.3 Findings

Three interconnected themes were derived from the participants' accounts. Each of the themes reflected perspectives across all participants' accounts. The first theme: 'We are all part of the sea', represents individuals' interconnectedness and shared experiences of death and dying conversations. A central tenet of this theme is that individuals are not isolated entities but rather interconnected elements within a larger system, akin to how different entities exist within the vastness of the sea. This theme explores how individuals perceive themselves and others in a broader context; in essence, how participants understand their interconnectedness with others, how shared experiences shape their identities, and how these connections influence their lived experiences. By exploring the theme of 'We are part of the sea', I uncovered deeper insights into how individuals construct meaning, relate to one another, and navigate their shared existence. The second theme: 'Shifting death and dying conversations perspectives', delves into the evolving nature of discussions surrounding death and dying from the perspective of individuals experiencing or witnessing these phenomena. This theme explores how people's views, attitudes, and approaches towards conversations about death and dying transform over time or in response to different life events. The nuanced shifts in individuals' perceptions, emotions, and communication styles regarding death and dying emerged as I explored how personal experiences, cultural beliefs, societal norms, or life events influence individuals' conversations about mortality. In addition, the impact of changing relations, personal growth, or external influences on individuals' discussions about death and dying was identified. The third theme, 'Holding hands with death and dying', encapsulates individuals' connection with the concepts of death and dying. Central to this theme was the complexity of death and dying conversations' including the emotional, psychological, and existential influences on participants' accounts. As I explored how individuals experience comfort, fear, acceptance, or resistance when dealing with death and dying conversations, the deep emotional and existential implications as participants revealed how they navigate death and dying conversations came to light. By exploring how individuals engage with their mortality, grapple with existential questions, and seek meaning and connection in the face of death and dying, I uncovered individuals' lived experiences, perceptions, and inner struggles as they held hands with death and dying. The key element of this theme invites a reflective examination of the human experience in the presence of mortality, highlighting the vulnerability, resilience, and transformative potential inherent in facing the end of life. By delving into the nuances of holding hands with death and dying, I can illuminate the complexities of the human experience in confronting mortality and the existential journey toward the inevitable end (see Figure 5.3).

Each theme will be described considering the main aim of the thesis: to explore the lived experiences of death and dying conversations. Extracts from the participant accounts will illustrate the meaning of these themes, enhancing the credibility of interpretations.

Figure 5.3

Presentation of themes and subthemes



5.4 Theme 1: We are all part of the sea

The theme 'we are all part of the sea' encompasses participants' perspectives on death and dying and how they engaged with the reality of death in their lives. Across participants, there was a recognition that death is an inevitable part of the human experience and that by confronting and accepting its reality, life can potentially be lived more fully and authentically. Participants reflected on their personal values, priorities, and relationships and considered how they might make conscious choices about approaching the end-of-life and related death and dying conversations. Reflecting on one's own 'Being toward death and dying' conversations appeared to help individuals navigate end-of-life decisions, plan, and find meaning in the face of mortality.

5.4.1 Individual, Societal and Cultural constructs of death and dying

Individual, societal, and cultural constructs of death and dying encompass a complex interplay of personal beliefs, social norms, and collective values that shape how individuals perceive, experience, and navigate death and dying conversations. Many participants perceived that, as a society, we resist talking about death and dying, and there is a fear of facing death and exploring its meaning. For example:

"So, you know, people don't like to get upset as well; there's maybe, you know, we sort of that English reserve as well." Stella, individual interview.

People avoiding '*getting upset* 'and displaying an *"English reserve"* appears to reflect a cultural tendency towards emotional restraint and a reluctance to express feelings of distress or discomfort openly, maintaining composure, stoicism, and emotional control in the face of challenging situations. This reserved demeanour may stem from cultural values emphasising self-control, privacy, and the avoidance of overt emotional displays in public settings.

There appears to be a delicate relationship between emotions and cultural norms and how they can impact how individuals convey their feelings. In the focus group, Stuart articulated that humans tend to resist talking about their mortality, which reflects a common distress or denial regarding the inevitability of mortality. Furthermore, he suggested that when faced with our mortality, individuals react with hesitation or avoidance:

"There's, there's, just that that natural humankind of emotional response actually, I didn't want to talk about my death, that I don't want to recognise I'm going to die." Stuart, Focus Group.

This reluctance to recognise our mortality and the fear of discussing death seems to relate to deep-seated fears or existential anxieties. Many participants recalled accounts of conversations about death and dying being avoided or blocked. Stef described a situation where her father-in-law became ill, and she observed that within the family, death conversations were absent. He deteriorated rapidly after diagnosis, which may have hindered the family having the emotional resilience to broach these discussions:

“But as a family, when I look back now, we actually didn't really have any conversations at all.” Stef, individual interview.

This lack of openness to death conversations could contribute to misunderstandings or unaddressed emotions regarding death and suggests a historical pattern of silence or avoidance of the topic. Stef shared her family’s reactions to her father-in-law's illness; for example, her mother-in-law avoided and used distraction when Stef tried to initiate conversations about death and dying. This type of avoidance was also highlighted by Joseph, who remembered as a child that, adults avoided discussing death in front of him, suggesting they wanted to protect him from the emotions that death can evoke. *“when I grew up, it was a taboo…….it was never talked about”.* He went on to say that when he was younger, elderly people ‘would just disappear: *“they wouldn't die. They would go into a, into a nursing home, or something like that or whatever.”* Joseph shared his later struggles in discussing death with his mother, who seemed vehemently opposed to the word itself.

The notion that older people vanish without acknowledging their mortality further supports the idea of families avoiding or the denial of death and death conversations. In addition, referring to nursing homes as places where older adults "*go*" highlights a sense of detachment or separation from the process of ageing and a distancing from the person who may be moving closer to the end of their life. These viewpoints shape a narrative where ageing and approaching the end-of-life are seen as processes of isolation or concealment rather than acceptance and comprehension.

Similarly, Stella tried to articulate how, in our (UK) culture, we naturally do not talk about death or dying and suggested death is viewed as something sinister. Consequently, with a lack of open talk, it becomes unknown, and the unknown can become something to be feared, resulting in death conversations being avoided:

“Particularly in our culture, we can be quite scared about, about that, the, the dying side of thing …. There's this real dark …. we've we something we've got an intuition about these things in some ways, and then we make turn it into a fear of, I think, by not addressing it.” Stella, individual interview.

The association of death being a *"real dark"* aspect of life suggests a deep-seated apprehension or aversion to death that may stem from societal taboos, existential uncertainties, or ingrained beliefs that contribute to a sense of foreboding or anxiety surrounding death. By avoiding discussions, we perpetuate negative perceptions and emotions surrounding mortality. Stella perceived there seems to be a loss of connection when a person dies with '*we've lost quite a lot of those connections, and in with the body and embalming….and caring'*, which has diminished over time. Though she acknowledges that these rituals could be difficult and painful, and not everyone would want to participate, there is likely to be a sense of loss for some in not being able to experience this aspect of death, not least because of this proximity to the deceased enable a more open attitude to 'Being with death'.

5.4.2 Spirituality and religious influences on experiences and perceptions of death and dying

A prominent feature of participants' accounts was the way spiritual and religious beliefs were perceived to shape experiences of and perceptions about death and dying. Participants articulated religion as a connection or relatedness with something greater than themselves. At the same time, spirituality was typically perceived to be associated with a deep sense of interconnectedness with the world, nature, other beings or the universe. Angelica summarised this by linking her spiritual conviction or confidence in the existence, goodness, or reliability of something beyond what can be directly observed, proven or directed by religious leaders or texts. For Angelica, spirituality and spiritual care involved indescribable energy entwined with life purpose, meaning and hope:

"Spiritual care to do with purpose and meaning……. offers hope that thing that keeps us going ……. energy that runs through those people trees stones animals." Angelica, individual interview.

Participants highlighted this notion of spiritual care offering or supporting hope and promoting optimism and resilience in the face of life's challenges. Furthermore, the imagery of energy flowing through nature, "those people, trees, stones, animals," conveys a holistic interconnectedness that rises above individual boundaries and the human psyche.

Spirituality is a complex and deeply personal concept that can shape an individual's beliefs, perspectives, and experiences. Within the focus group, there was agreement among participants that spiritual beliefs do not seem to be embedded into care, and is a neglected component of care which needs addressing. However, there appeared to be a sense that practitioners must embrace their spirituality and identity before they can recognise and acknowledge the importance of spirituality in another, "*get practitioners to be comfortable with, with, their own spirituality with their own identity".* Embracing spirituality and identity was thought to enhance authenticity, empathy, and understanding in people's interactions with others and, as such, may help create the space to engage in death and dying conversations.

Spirituality and religious beliefs were acknowledged as separate concepts, although they were often used interchangeably in practice. Angelica's accounts touched on how modern society has influenced the evolution of religion and suggest that people sometimes make their spiritual paths from the interplay of spirituality and religion/faith influenced by life experience:

> *"People were in this era of pick a mix of where people can take a little bit of Hinduism and mix it with solar system and, and a bit paganism there and assemble from that here, and my grandma told me this and I read this. And then they mix it up (spirituality and religion)." Angelica, individual interview.*

Angelica's recollections of learning from her grandmother and personal readings for her resulted in a multi-faceted exploration of spirituality that integrates familial wisdom, personal research, and diverse spiritual and religious influences.

This unique individual construct of beliefs was similarly highlighted in Joseph's accounts, which revealed that despite being brought up in the same family environment, there were "*diametrically opposed"* perspectives on faith and spirituality between him and his brother:

> *"We had completely a diametric opposite, diametrically opposed. He has no faith. I have a faith which was always made for some interesting conversations." Joseph, individual interview.*

Fundamental differences in beliefs, whether spiritual or religious, acknowledge how the environment we occupy within and outside of our family can impact discussions about death. Exploring how contrasting belief systems shape interactions and perceptions can offer insights into the complexities of human relationships. The sibling relationship allowed the sharing of diverse viewpoints without the fear of stigma or conflict.

Death is a profound and universal topic that can be challenging to discuss explicitly, especially with people we do not know well. Analogies can help to understand the complex concept of death and dying by relating to something more familiar. Rebecca's and Stella's accounts referenced water as an analogy to life forces. Stella's analogy to life was humans being part of the sea; "*we are all part of the sea, and when we are born, we take a bucket of seawater, and when we die, we put the bucket of water back into the sea*." Rebecca identified herself as separate from the river but ultimately still part of the world in that she is part of the river, but within that river, she is still separated by a vessel:

> *"I'm in a river, and, and I'm like a little test tube. I'm, I'm, the test tube of, of water going down the rivers, so the test tube kind of keeps me separate from the rest of the river. But what's in the test tube is actually the same as what's in the river, and that, when I get down to the sea, the test tube will go, but I'll be there in the sea. That's my …... That's my sense of it." Rebecca, individual interview.*

Analogies appear to encourage personal reflection and philosophical exploration for self and others. Stella connected to the use of analogy when dealing with grief. She believed '*we are a jar, and grief fills the jar*'. Over time, the grief remains the same size, but the jar has become larger. This gives the impression of contradicting the river analogy from something free flowing to something that is contained but connects with Rebecca's '*test tube'* concept as something that can be held within and released:

> *"There was a lovely Facebook post of a jar, you know, and people think that this, you know, that grief, gets smaller, but it's not. It's just your jar. It gets bigger. Just that as a, a little analogy for, for people can just again just". Stella, individual interview.*

These analogies challenge societal perceptions that grief fades with time but highlight the enduring nature of grief as a significant and expanding part of one's emotional landscape. The metaphor invites a revaluation of how individuals understand and navigate the complexities of grief, emphasising the ongoing nature of the grieving process. In contrast, Joseph's narrative depiction of a dead loved one as a bird suggests that some people might associate perceiving a specific animal as representing their loved one returning to visit them:

“We had an experience …. we kept seeing this Robin in the garden. It was one of those I know It's a lovely and one It's a lovely serendipitous things, or just of complete coincidental things. But it was after my partner's mother had died, and there was always a robin in …. the garden.” Joseph, … individual interview.

The recurring presence of a robin in the garden following the death of Joseph’s partner's mother holds symbolic significance and meaning for him. The robin appears as a *‘serendipitous’* or *‘coincidental’* occurrence, suggesting a sense of spiritual connection or synchronicity with the departed loved one. The bird's presence may be interpreted as a comforting sign or symbol of his partner’s mother's continued presence or spiritual presence in the lives of those left behind. Joseph’s narrative incorporated a sense of disbelief and cynicism. Still, he also suggested that if these representations help people deal with death, they should be considered a source of comfort.

For other participants, there was a belief that there is life after death, offering a sense of hope that ‘*something lovely is waiting’* for us after death:

“I think it's also hope. That is a real, tangible hope………….. that there is something rather than nothing.” Angelica, individual interview.

Angelica reflected on the concept of hope as a tangible and significant aspect of human experience. By emphasising the idea of hope as a tangible entity, Angelica alluded to the profound impact that hope can have on shaping one's outlook on life and navigating existential questions. The reference to *"something rather than nothing"* hints at the existential contemplation of existence and the human desire to find meaning and significance in the world.

Life experiences can evoke a range of emotions, including grief, fear, or acceptance, and influence beliefs about the meaning of life, the afterlife and the nature of death itself. Joseph suggested his brother died content with his life and how he had lived it:

“He had to had a very successful career and a very successful family. He'd been married for nearly fifty years. …. Yeah, four lovely daughters, grandchild, and all the rest of it. And he did feel content in that way, and that's you know. So, he wasn't going raging into the night. He was because he felt content.” Joseph, individual interview.

This narrative highlights the importance of personal relationships, fulfilment, and emotional well-being in shaping one's perception of a life well-lived and approaching death with a sense of peace and contentment. Dillen and Stella echoed Joseph's accounts about contentment with life, expanding that some people may not have a *good death* because of missed chances, regrets and lack of opportunity to reflect on life positivity as they move towards their dying experience.

5.4.3 Death and bereavement preparation and positivity

Recognising death as an inevitability can help individuals come to terms with their mortality and make choices that align with their values and priorities. This can involve making arrangements and decisions to ensure that end-of-life wishes are respected and that loved ones are supported during and after the dying process.

Angelica, however, shared the experiences of some of the patients she cared for in a hospice setting who had considered the end of their life. She wonders whether these patients had a fear, not only of death but because they were entering a hospice and what that meant. Stef discusses the unpredictability of mortality, for example:

"I mean you know we're both, I said we're not old but that doesn't matter it's not about age, because anything can happen to anybody at any time." Stef., individual interview.

Stef talked about how unforeseen events can affect anyone at any time, highlighting how fragile and uncertain life can be, regardless of age or stage of life. Whilst it is impossible to control circumstances, individuals can influence how they respond. The focus group participants highlighted that being prepared for death and dying was important as it allowed people to live their remaining lives knowing that if anything happens, everything is '*ready*' for the ones left behind,

"All the practical's to do I've cleared out four family houses in the last three years, all that kind of stuff but getting things ready so it's easier for the next generation." Stuart, Focus Group.

Across participants' accounts, there was a sense of duty in preparing for the future through sorting through family homes and taking care of practical/legal responsibilities. Stuart's management of family assets and possessions suggests a dedication to arranging and managing family properties. Through these efforts, Stuart discusses an approach focused on streamlining and structuring the estate/property to benefit future generations. Participants' accounts of managing their affairs seem to reflect care, foresight, and planning for a legacy aimed at preserving family and passing on responsibilities to generations in a considerate and orderly manner. This systematic approach to considering death and dying openness around after-death formalities may be more alluring for individuals to talk about, who may otherwise be resistant to death openness.

Across participant's accounts, death was described as an inseparable part of life's cycle. Stella used the analogy that life and death are interconnected, like heads and tails, two sides of a coin. This perspective on death highlights how it gives meaning and significance to our existence. Angelica revealed that when caring for people who want to discuss death and their mortality, they seem to face death head-on, but other people who deny death may view it as not real. Avoiding conversations about death may in some way prevent its inevitability; Stella seemed astonished that people do not seem to understand that death is part of life:

"Range from people are just looking death in the face, and they want to talk about it, and I want to plan the funeral, but there's a good number who come in, and it's, it's in their minds it's not happening, it's not real I can't believe this is happening." Angelica, individual interview.

This extract captures the diverse range of responses and attitudes individuals may have when facing death; Stella expanded by explaining for some, "*death is an enemy of life", w*hich suggests that death is an adversary to life. For those who have experienced loss, fear of the unknown, or hold beliefs that emphasise the finality and end-of-life, then viewing death as the enemy appears plausible. This perspective can evoke feelings of fear, grief, defiance, and resistance towards death. However, Stef perceived that if you talk about people's wishes when they die, those left behind will not have to deal with uncertainty about them. Participants alluded to whether death is seen as a friend or an enemy, individuals may hold a combination of both views, and their perceptions may shift over time.

How we engage in ritual and remembrance surrounding death and dying can influence our openness to death conversations. Several participants' narratives included discussions about funerals and their purpose to commemorate and honour the deceased person.

Stella recounted attending a ball to celebrate a friend's life, which was tagged as a living funeral. This living funeral may have provided Stella with a deeper appreciation for the transience of life and the importance of cherishing moments with loved ones. Similarly, Rebecca described her husband's funeral, which was not held in a traditional religious setting but in a woodland. Friends and family were involved in planning and contributing to the funeral. People shared their enjoyment of the ceremony, *“It was beautiful. It was just lovely. It was a real celebration of his life, and our life.”* By describing the event as a celebration of "*our life*", Rebecca draws attention to the unity and shared moments that bound them together, highlighting the significance of coming together to commemorate and cherish the richness of life experiences. This portrayal reflects a positive and affirming perspective on the power of communal gatherings to honour, remember, and celebrate the lives of loved ones. However, there were mixed feelings and guilt about having enjoyed the funeral:

“But there's a strange guilt for having enjoyed it, you know.” Rebecca, individual interview.

This conflicting emotional experience suggests an internal tension between the positive feelings of enjoyment and an underlying sense of unease or remorse. The juxtaposition of pleasure and guilt may stem from various sources, such as societal expectations, personal beliefs, or past experiences that influence one's perception of what is deemed acceptable or appropriate. This internal conflict highlights the complexity of human emotions and the intricate interplay between different feelings that can coexist within an individual's psyche.

In contrast to Rebecca, Dillen described a sense of sadness about the funerals he had attended. He reflected on the eulogy and learning of loved ones’ lives previously unknown; he appeared to regret not knowing the person when they were alive. This promptly Dillen to consider the value of living funerals, which celebrate a person’s life with them before they die:

“And then it's only when someone dies that that suddenly they realise. Oh, actually, I really would have liked to have known this or that.” Dillen, individual interview.

To some participants, it appeared that when someone dies, there is a belated comprehension of the key aspects of the deceased life they wish they had known or experienced ‘in the living’. This realisation may encompass unspoken conversations, unresolved issues, unshared memories, or unexpressed emotions that individuals may regret not addressing earlier.

In discussing funerals, participants naturally progressed their discussions into end-of-life care. This shift in focus resulted in participants considering not only the support dying person but also the family supporting them that needs care:

> *"Hospice absolutely transformed my view of what was possible and, and it also really held a mirror up to, to, to, the clinical care that my mum had. Actually, what she needed and what we needed was a whole raft of family-centred well-being care……… that, that's kind of we needed care and health and love around." Stuart, Focus Group.*

The decision to transfer Stuart's mother to a hospice for her final days suggests a need for specialised care and support during this critical time. The reference to "*care, health, and love"* highlights the multifaceted aspects essential in end-of-life situations, emphasising the importance of comprehensive support that encompasses physical, emotional, and relational dimensions. This reflective account reveals Stuart's deep sense of longing for a more ideal and nurturing end-of-life experience for his mother, emphasising the enduring significance of providing comfort, dignity, and love in the face of death and dying.

Based on their perceptions, experiences and understanding of hospice care, participants discussed the medicalisation of death and grief. Stef spoke about changing practices, highlighting that "in years gone by", the body was kept in the living room, often with a family member in vigil. In today's Western society, typically, funeral directors remove the body, with the family not involved in cleaning or clothing the body; "*all just slowly got put behind doors*". The phrase "*put behind doors*" implies a sense of distancing or removal from the immediate care environment, symbolising a shift towards more formalised or institutionalised procedures related to death and funeral arrangements. The focus group participants discussed the ageing of the population and how society will be exposed to death more regularly, as witnessed in the recent COVID-19 pandemic. Participants perceived death has become medicalised; deaths occur in hospitals rather than at home. We use fruitless medical treatments near death and reduce the involvement of families and communities in the dying process. With the creation of the NHS, perhaps death is seen as something that should be fixed:

> *"But over in the UK death has become so medicalised over the last 50/70 years certainly since we've had the NHS you know death is something that doctors deal with, undertaker's deal with Alison touched on it, they will come and take the body away." Stuart, Focus Group.*

Stuart highlights a shift in which death has become primarily associated with health professionals, such as doctors, nurses, and funeral directors. The process of death and caring for the deceased has become more institutionalised and formalised, with health professionals and undertakers taking on key roles in the process.

Grief is a natural and complex emotional response to loss. It is a profound sorrow and intense emotional pain that accompanies the experience of losing someone or something significant to the individual. Stella and Angelica perceived grief needed to be reframed; for Stella, her insight and views of grief before working in the hospice, where grief would regress as you moved through life. Her hospice experience shifted that perception, and she now views grief as something that stays the same size or even grows, and as the person's life moves forward, they can encompass that grief.

“That some people find that …. grief doesn't go away, and it's this idea that actually you're, it's not that grief gets the grief. Doesn't get smaller. You know that that that hurt. But what you find is that you grow bigger around it.” Stella, individual interview.

The phrase "grief doesn't get smaller" indicates that the pain and sadness experienced after a loss can persist. This growth hints at a passage of growth, resilience and adjustment in response to loss. The image of "*you grow bigger around it*" conveys a feeling of expansion, strength and the ability to embrace grief within a sense of self. Similarly, Angelica perceived that comprehending grief goes beyond the funeral; it progresses throughout life. Furthermore, she highlights that grief is not solely tied to someone’s death but also pertains to those who receive a diagnosis of a life-shortening illness. Dillen similarly emphasised the importance of allowing time to mourn. As Stella revealed, grief remains constant while the individual grows stronger and learns to coexist with it over time. Participants alluded to grief never disappearing; the person learns to live alongside the grief. As Rebecca states, *“It pops up, you know. Yeah, it pops up”.*

Participants' narratives highlighted that grief does not dissolve but changes, and as individuals, we also change as that experience is reflected upon. We grow through it, with it, in and amongst the life experiences we encounter after the dying and death event.

In association with this seeming openness toward discussing death topics, the death positivity movement was seen by some as a supportive movement and a place to be able to talk freely about death and dying. Participants discussed events/times where they had been supported to have an open conversation about the end-of-life. However, many participants had not heard of the expression death positivity movement.

"It's not one I've heard of certainly, but I have no problems with it no." Joseph, individual interview.

This was quite revealing because all the stakeholder participants work in areas that foster open conversations about death, engage in end-of-life planning, and cultivate an attitude of acceptance, gratitude, and a deeper appreciation for the preciousness of life. Alison and Dexter were more aware of the term death positivity movement but shared that they rarely used the term death positivity movement but did embrace its philosophy. Stuart and Paul interpreted the words death positivity movement literally, highlighting that death could be positive, and could see why the term is beginning to be used with health professionals:

"I've definitely seen the word lots of times, uhm, I don't we don't really use it very much I can say I embrace it I, I, understand where it's coming from it's kind of to counter the death denial and death phobic nature of our society." Paul, Focus Group.

By recognising the need to address death denial and fear, Paul revealed a willingness to explore alternative perspectives that promote a healthier relationship with death and dying within the broader societal context. However, the focus group was still hesitant to use the terminology 'death positivity', as it could have negative connotations for individuals, for example:

"Is peculiar and unsettling it's not it's not it's certainly not a phrase I would use in my professional work at all, I think I think I can understand what I think you think it means but it's not a phrase I'd be comfortable to use." Stuart, Focus Group.

Although Stuart and Paul work in the health sector, there was hesitation to use the term death positivity. While Stuart and Paul were open to talking about death and dying and undertaking teaching on death and dying, they were not comfortable incorporating death positivity terminology in clinical practice. Alison supported the discussion, highlighting she does not use the term in practice because of possible negative connotations in how people may perceive death as positive.

Stef and Stella mentioned that individuals would 'close down' (not want to talk) as soon as death was mentioned, and others could not understand how death could be seen in a positive light. Using death positivity terminology, Stella perceived the ethos behind the terminology of death positivity but wondered how to make it palatable to the public, as death positivity is a niche phrase. For Stef, she felt that, as a society, we should be using language to normalise death and dying:

“I actually sort of said, you may, may, or may not agree with the terminology, however, we have got to get used to using those word.” Stef, individual interview.

Even though some participants felt that the death positivity movement had some negative connotations, participants highlighted that the movement allowed for opportunities for the voice of dying people to be heard, which is invaluable to help facilitate reducing death anxiety, as Steven revealed, *“It's for me important and helpful framework of thinking”.*

5.5 Theme 2: Shifting death and dying conversational perspectives

This theme explores participants' narratives about navigating the subjects of death, end-of-life care, sorrow, and loss. These conversations include sharing experiences, feelings, and beliefs and highlighting how dialogue is pivotal in nurturing comprehension, compassion, and assistance for those confronting mortality.

5.5.1 Types of death and dying conversations.

Participants described a range of conversations related to mortality, end-of-life care, grief, and loss. This includes practical discussions about advance care planning, emotional conversations about coping with grief, philosophical reflections on the nature of life and death, and supportive dialogues to provide comfort and understanding. In addition, the COVID-19 pandemic from 2020 onwards altered how participants reacted and responded to death and dying conversations. Stef reflected on the realisation that the pandemic affected many people and that death was not just associated with the old, as people were dying from COVID across the lifespan. While acknowledging the devastating impact of the pandemic on individuals and families, Stef also perceived people came together, uniting against a devastating situation akin to the “*good old days*”.

“The positive aspects of that I think has been that we have in some ways, got back to how it used to be and that we're seeing death on a day to day basis in terms of numbers and the effects and the storytelling that we've seen on the new.” Stef, individual interview.

What appears to be alluded to is that with a greater presence of death, individuals may develop a greater appreciation for life and possibly a deeper sense of empathy. Most participants perceived death conversations increased, and the pandemic positively affected death openness. Stella highlighted, *“So, death was a lot more talked about.”* For Stef, it was about what people may have learned from the experience:

> *“I think I think it helped reinforce how important it is to have the conversation. And I hope that some you know, even if it's made people go away and even if we talked about today do a power of attorney or go actually go and do wills.” Stef, individual interview.*

However, the focus group participants appeared to have contrasting opinions. As respected by Stuart, collectively, they agreed that *“we've had a lot of narrative that people will talk more about death now”* but perceived there had been no increase in meaningful discussions:

> *“that's been beneficial and I’ve seen no evidence that the that the media attention around death has created any upsurge in public appetite to those conversations on a personal level at all.” Stuart, Focus Group.*

It could be suggested that while media coverage raised awareness and prompted social reflections on mortality, it did not directly impact the individual readiness or comfort in engaging in conversations around death and dying. Stef also thought that because the pandemic was no longer in the news*, “it seems to have disappeared again as its background”* and that the public was no longer talking about death and dying.

A key feature across participants’ accounts was that death conversations, both pre and post-COVID, were viewed as negative. If death was broached, it could have an impact on relationships, as highlighted by Angelica:

> *“The trust was broken, sadly, but I did manage to kind of salvage the relationship as long as I kept to normal general conversation and the weather and things like that, but that, that was his spiritual need.” Angelica, individual interview.*

Alternatively, Joseph suggested that the more you talk about a topic that worries you, the less you tend to worry. He perceived that if we talked more about death and dying, then what is seen as a very daunting topic would become more palatable and easier to manage:

> *“The more you have the opportunity to talk about something. Um, that worries you, the less worrying it becomes it. Could. You can reduce something that looks enormous down to something, a bit more manageable and palatable. I think.” Joseph, individual interview.*

This perspective highlights the therapeutic value of communication and the potential for conversations to transform worries into smaller, more manageable challenges. Joseph highlights that, for a considerable number of people, the impetus to think about mortality and engage in discussions about death often arises when faced with the reality of a life-shortening or as they approach older age. Joseph highlights the role of personal experiences and life transitions in shaping individuals' attitudes and preparations for the end-of-life:

"And somebody younger who had something to do with that things still to do and still to and that's, that's a different, That's a different question altogether." Joseph, individual interview.

Joseph suggests that age and life stage play a significant role in shaping how individuals approach discussions about death and the existential questions that arise from considering one's mortality. For Steven, however, discussing death was a normal part of his family narrative:

"I've definitely never had any hesitation talking about it. I've always been. I've always been inherently quite comfortable, so I chat to my parents about what we're going to do when they're towards the end-of-life, and, you know, talk really openly about who's going to die first? And what should we do if you die first, and what we do if you die first…….. I come from a family in which that's quite normal." Steven, individual interview.

The willingness to openly talk about end-of-life plans and considerations with his parents illustrates a sense of readiness and acceptance regarding the inevitability of death. By engaging in discussions about death and planning for end-of-life scenarios, Steven validates a proactive approach to addressing important family matters. His comfort in discussing these topics indicates a culture of openness and preparedness within their family, where conversations about death are normalised and viewed as a natural part of life.

Within the focus group participants, death and dying conversations appeared commonplace within their households. Participants described death conversations as 'a given' within the family. This was highlighted by Alison, who articulated that death and dying conversations make you face your mortality and give credence to the importance of these conversations.

"When you're confronted with your with those aspects of mortality I think that's when you, you, realise, you should have these conversations you've got to have them." Paul, Focus Group.

Paul reflects that when individuals are confronted with the fragility and impermanence of life, they understand the significance of discussing death and dying. There is an implication that moments of reckoning with mortality can prompt individuals to acknowledge the necessity of having conversations about important end-of-life topics.

5.5.2 Barriers to death and dying conversations.

Individuals' lived experiences and perspectives as they encounter difficulties in addressing death and dying conversations were explored. Joseph, Steven and Angelica described the barriers to death and dying conversations, including fear of the unknown, being morbid and not knowing what to say, not wanting "*to upset anybody*", and the fear of pain. Angelica expanded by highlighting the fear that people may have that could hinder conversations. Using an example of visiting a patient and initiating a conversation regarding death and dying, she was asked to leave the room. "*I don't want to be negatively influenced or something like that, you know*". Angela perceived the patient deemed this conversation negative and did not want to enter the discussion. It could be inferred that the patient was in denial or was just fearful of death, or the timing was misjudged and perhaps needed to be introduced at a slower pace.

Similarly, Stef recounted a conversation and the barriers the family experienced when a discussion with the GP focused on the Do Not Attempt Cardiopulmonary Resuscitation with her father. His diagnosis was unexpected, and her family were faced with a rapid decline in health:

> *"I remember him (dad) saying actually to me uhm, quietly one day he said to me, oh Stef he said, please don't talk to this (DNACPR) please don't talk to to mum about how I am and how I'm feeling I don't want to upset her." Stef, individual interview.*

This captures the dynamics of family relationships and how individuals balance their emotional needs with caring for others. It emphasises the importance of empathy, kindness and understanding within families, highlighting how people show care and protectiveness toward their loved ones. Stef continued her account by highlighting that one of the problems that hinders death and dying conversations is not knowing what to say and when to say it.

“But I don't know how I don't know how to move forward with it, I don't know what to say I don't know how to say it.” Stef, individual interview.

This narrative is reflexive of how people struggle when dealing with the emotions of situations, emphasising the importance of patience, self-awareness and seeking help to navigate emotionally challenging circumstances. Rebecca suggests that there is also a tendency in society to avoid discussions about death and mortality due to concerns about norms:

“And I think it's something actually about social acceptability ……………..it's often seen as being oooh we don't, we don't talk about it, we don’t want to look at it, we don’t want to talk about it, and or you're potentially seeing as being a bit almost antisocial really.” Rebecca, individual interview.

Rebecca went on to say that death is on the list of topics not to be discussed, such as religion and politics. Stella echoed this: *“I mean, yeah, the whole thing about not making to want people feel awkward.”* By expressing a desire not to contribute to this discomfort, Stella highlights a sensitivity to the emotional nuances and social dynamics involved in addressing challenging subjects.

For the focus group participants, it was perceived that death is only talked about when it is imminent. For example:

“I mean they, they, do when it's imminent, and not everybody even does that but that's usually when most people start talking about it when it's imminent for them, or for somebody close to them.” Alison, Focus Group.

Not everyone engages in conversations about death, but it is common for people to start talking about it when it becomes a pressing concern.

Resistance or discomfort regarding death and dying can also be a barrier to death and dying conversations, as revealed in the following extract:

“I’ve got my own family I’ve tried to have this conversation with my sister and I’m getting a will sorted out and she's ‘oh stop talking to me as though, as though you're at work.” Stuart, Focus Group.

The difference in how Stuart and his sister communicate about end-of-life matters highlights the challenges when addressing death-related topics within families. Stuart continued his account by revealing that:

“There's the thing about having a conversation with somebody who knows you as well you know I think often it’s much easier with a stranger because then you can share your hopes and fears and deepest dread and with not having to face that person again the following week.” Stuart, Focus Group.

Stuart’s account highlights differences in sharing hopes, fears, and vulnerabilities with someone you know versus a stranger. Stuart’s viewpoint highlights how familiarity and vulnerability intersect in communication.

Age can be seen as a barrier to death and dying conversations. Rebecca talked of a conversation she had with a friend when they spoke of dying when they were younger. Rebecca’s friend shows a shift in attitude towards ageing, mortality and decisions about the end-of-life.

“I had another conversation actually she was quite a good friend thinking about it, and when we were younger she always used to say she was going to end her life when she was eighty……..because she didn't she didn't want to go in the get to the old age and all those problems………now she's in her mid-seventies, but suddenly the idea of topping herself when she's eighty doesn't seem to have the appeal that it did before.” Rebecca, individual interview.

This transformation highlights how thoughts about the end-of-life are not fixed but can change over time, emphasising the importance of reassessing perspectives and priorities as circumstances evolve.

Several participants highlighted terminology as a further barrier to death and dying conversations. Angelica perceived that words to describe death needed to be chosen carefully and used in a way that people could understand what was being said, and this was not just for patients. She talks about the use of the word “*death”* and that it needs to be used more in everyday conversations. She felt that using language more frequently diminishes its power, making it easier for people to engage in discussions about death and dying.

“Think we've just got to get a little bit got to get used to get over the fact that it is a word that we need, we need to use because if we speak a bit more openly about it, we do, do, use those words, I think, will find things become a little bit easier, maybe I don't know.” Stef, individual interview.

Steven then talked about the use of positivity and how it can give the wrong impression, *“people feel like they have to sort of be really sort of into it.”*. Steven points out that encouraging an outlook on death might inadvertently pressure people to adopt or enthusiastically support this mindset. The phrase *"into it"* suggests a level of involvement or enthusiasm that some individuals might feel compelled to exhibit when faced with the notion of embracing death. Acknowledging and validating various emotional responses and attitudes towards death can help create a supportive and inclusive environment for exploring this complex and deeply personal topic. He went on to reflect on the euphemisms that are used in connection with death and dying, giving a false positivity commonly observed in discussions surrounding death and loss.

"Lot of the year sort of euphemistic language that's used, and, and also the sort of some of the sorts of slightly false positivity that's used in the often in those sorts of situations, you know your classic sort of Oh, well, they were comfortable, or you know Xyz is what they would have wanted, or they were surrounded by their loved one." Steven, individual interview.

Expressions of comfort can sometimes gloss over the raw emotions and challenges inherent in dealing with death, offering a veneer of comfort or closure that may not always align with the multifaceted nature of grief and loss. By drawing attention to these common phrases and communication patterns, Steven points to the importance of approaching discussions about death with honesty, sensitivity, and authenticity while acknowledging the nuanced and varied ways individuals experience and express their emotions in the face of mortality. He went on to say his friend's emotional reaction to a difficult situation involving the death of their father, using words like "*horrendous*" and "*horrible*" to express the intense and distressing nature of the experience. However, they felt pressured to conform to certain societal expectations or norms regarding how they should discuss or portray the circumstances of the death of their father.

The participants all talked about their perceptions of conversations about death and dying with children. Stef suggests that children are perceived as too young to start having these conversations, implying a societal hesitation or reluctance to introduce certain complex or sensitive subjects at an early age.

"I know a lot of people sort of think that you know some children are a bit too young to start having these." Stef, individual interview.

This viewpoint highlights the importance placed on age-appropriate communication, emotional readiness, and gradual introduction of difficult topics to ensure that children can navigate and comprehend such discussions in a supportive and understandable manner. Stef, Joseph, and Rebecca all felt that having conversations with young children should happen if they are done in a way that is appropriate for their age:

"You know children can deal with almost anything, so it's like, Why not just tell them the truth?" Dillen, individual interview.

This ties in with a comment from Stella:

“But one of the things I remember is about the importance, the kids. It's just that practicality, you know. Kids may be really fearful, and we're like oh, thinking it's about this actually, It's like they just need to know.” Stella, individual interview.

Stella suggests dispelling misconceptions and offering age-appropriate explanations can help alleviate children's anxieties. The focus is on the idea that children's fears can often be rooted in misunderstandings or lack of information. By offering children accurate and accessible knowledge, they can better comprehend and navigate their emotions surrounding death.

5.5.3 Facilitators of good death and dying conversations

Through death talk, individuals co-create meaning by articulating their thoughts, feelings, beliefs, and reflections on mortality. The positive dynamics of sharing in discussions about death, including self-reflections, generational openness, and education, can lead to personal growth, intergenerational understanding, and societal acceptance of the life stage.

All the participants agreed that education was the most influential facilitator of good death and dying conversations. For example, Stef implied that education is not only for the public but also for healthcare professionals.

“I think the education is not just about your general public and your health care professionals and all those sorts of people.” Stef, individual interview.

Dillen took this further by saying:

“I think there's, there's as much education there in terms of not just the death and dying, but just the different practices, the different understandings, and how people deal with it in different religions and different countries.” Dillen, individual interview.

Steven suggests that education would give people more of a choice “*and give people a little bit more of a sense of, of, of choice”.* He also went on to say that there is much work to be done in this area. Angelica also talked about the inclusion of children in education:

“I do feel it needs to be part of our conversation, even as children, just as, as we do, sex education, just as we, we learn how to work, our finances. It just needs to be part of the conversation because death is a definite.” Angelica, individual interview.

By incorporating death education into conversations with children, individuals can build resilience, empathy, and acceptance toward the concept of mortality, contributing to a more holistic and well-rounded approach to life's experiences. This follows on to the question at what age would be considered a good time to start educating children about death and dying. The focus group agreed that "*ideally from earlier from a very young age*". Steven suggested as soon as a child comprehends what is happening in their life.

"A good argument is to say, well, almost any age, you know I, as soon as a child has comprehension of what's happening in their life. It's possible that someone in their life dies, and so why would we not seek to prepare them for that in some way or other. Steven, individual interview.

The participants united and called for a more proactive approach to preparing children for the reality of death, acknowledging that early exposure to discussions about loss can contribute to their emotional resilience and understanding of mortality.

Participants considered a variety of ways in which they would facilitate conversations about death and dying. Angelica talked of media, workshops and offices. Stef spoke about music, books, the arts, being creative. Joseph mentioned that the 'right people' needed to be involved. Stella suggested a guide would be helpful. Rebecca talked about journaling. Steven spoke about making death and dying normal. He also talked about using celebrities to help as the public sees them as influential. He had seen how celebrities have helped with opening up discussion on mental health; could the same be done with death and dying? He mentioned the recent story of Deborah James. Debra James was a journalist who was diagnosed with incurable bowel cancer in 2016. She raised awareness of the illness until the day she died in 2022

"The Deborah James example this year is, is absolutely textbook in her. Her world, obviously so totally remarkable, and I think really for me, proves an awful lot of what I think is the theory behind it is that she talked about it as a normal thing." Steven, individual interview.

This approach could challenge the common taboos and stigmas surrounding conversations about death and dying. Deborah's willingness to speak openly about her experiences could be a powerful example of how embracing discussions about mortality can lead to greater understanding, acceptance, and support.

Most of the participants talked about needing a suitable space to be able to discuss death and dying. A place *“to be able to sit and make them feel comfortable,”* as said by Stella. Within the focus group, Stuart said:

“but also people need a space where there is a listening ear, at times, with no structure and no judgment and their values around it, because people are frightened and scared and they just want to talk.” Stuart, Focus Group.

This extract alludes to the therapeutic value of providing a space for individuals to share their thoughts and feelings about death without constraints or expectations.

One final aspect that several participants discussed regarding death and dying was creating memories, sharing stories and legacies and how talk and action around these activities could facilitate conversations about death and dying. Stef talked about the importance of memories. Rebecca talked about sharing stories of her husband and her life with her friends or others who have experienced the same thing. She was alluding to the fact that sharing helps to lessen the burden of grief. Stella said that sharing in a group context can help: “*A lot of people found that really insightful and useful and just hearing about other people's experiences as well”*. Stella also talked about legacies and her experience with a patient, for example:

“Who has got a little boy who's you know, um five, and making recordings for them, and doing, you know, doing those things that you know can give comfort to someone when you're not there for them. You know. I know people that written a letter every year, you know, until they're eighteen for their child. As they grow up things like that.” Stella, individual interview.

This example highlights the significance of leaving behind tangible expressions of love, guidance, and reassurance. These would be seen as a meaningful way to maintain a connection and support the children as they navigate life without their parents.

5.6 Theme 3: Holding hands with death and dying

Connections between death and dying can be seen as the deep bonds that people create with the ideas of mortality, grief, loss and the end-of-life. This theme covers the existential ties individuals share with the processes of death and dying on a personal level and in connection with others. Participants' lived experiences, perspectives and contemplations about mortality and its impact on one's identity, relationships and understanding of life’s limited duration are discussed.

5.6.1 Community readiness

The community offers a vital platform for sharing narratives, experiences, and cultural beliefs about death and dying. Individuals can collectively understand death and dying through communal discussions and rituals, drawing on shared values, traditions, and perspectives. It can also allow for communal engagement to transfer knowledge, wisdom, and emotional support, creating a sense of solidarity and interconnectedness in facing the universal mortality experience. Stef is a ‘community champion’, often involved in community work.

“Get people to network and support each other in times of crisis as a community rather than solely relying on the health service and the other services around that, so that's in essence really.” Stef, individual interview.

Stef emphasises the significance of nurturing community connections and assistance while moving away from formal health and social services. Cultivating an atmosphere in neighbourhoods can improve resilience, well-being and recovery for those in need. Stef recommends leveraging the resources and potential within our communities by tapping into the underused pool of knowledge, talents and support.

“We would use our communities. Tap into that wealth of our little treasure map of stuff that we have that we don't use.” Stef, individual interview.

Using a *"treasure map"* alludes to the idea that valuable assets and strengths remain untapped or undiscovered within our communities. By recognising and leveraging these resources, individuals and communities can address needs, solve problems, and enhance well-being through collective efforts and collaboration. Rebecca also talked about engaging in philosophical inquiries within communities as a valuable and enriching idea.

“There there was this thing around of having philosophical inquiries within communities. (Um-hmm) which I think is actually a lovely idea, and that's not something you don't see at all, it’s interesting flagging it up.” Rebecca, individual interview.

There is an implicit invitation to foster intellectual curiosity, critical thinking, and meaningful conversations that can deepen understanding, promote reflection, and cultivate a sense of shared exploration and learning among community members. Alison suggests that there is a need for improvement in how homes and neighbourhoods address the topic of death. Her observation highlights discussions and preparations surrounding death are often overlooked or handled inadequately within these settings.

“And homes and neighbourhoods need to get better at death.” Alison, Focus Group.

This perspective accentuates the importance of creating a culture that embraces discussions about death, fosters empathy, and provides resources to navigate the complexities of grief and loss within the familiar and communal spaces where people reside. However, Steven talks about the challenges of shifting societal attitudes.

“How do you shift and change socially broad social attitudes, so that society at large, and therefore people within it feel reasonably comfortable about death and dying.” Steven

By encouraging dialogue, education, and awareness initiatives, society can cultivate a more accepting and understanding perspective on death, increasing comfort and readiness to engage with these sensitive topics. This process of social change involves promoting empathy, communication, and acceptance to create a more inclusive and supportive environment for individuals to navigate the complexities of death and dying with dignity and respect.

Connection to others is a fundamental human experience that involves establishing meaningful relationships and fostering emotional bonds. It also involves sharing experiences with fellow individuals. Connections can foster interpersonal relationships, empathy, and communication, which aids in shaping an individual's belonging, identity, and well-being. Joseph talked about a vicar with whom he was friends with:

“He, he was not holier than that. Far from it, you know. It was the worst possible example, I should think. But that's the point, you, you know, because his faith was about his. His whole story was just about loving people, and that and that just it worked with him……..thousands of people who've been affected by this bloke, and hundreds and hundreds and hundreds of people have, you know, been married or baptised or buried by him, and all of the people of old, these people just love him, and just you know we're terribly moved when he did go.” Joseph, individual interview.

Joseph describes the widespread impact of this individual's actions, noting that he officiated at numerous significant life events for countless individuals and was deeply cherished by those who knew him. The emotional response to his death indicates the depth of connection and affection people felt towards him, highlighting his vital connection to others.

Stella also discussed how important connection is, conveying her appreciation for the opportunity to connect with a person before their death rather than learning about their life and impact after death.

"But how wonderful for them to be able to come and connect with that person rather than wait till they died and not be, and then hear about it. You know, however much all that love of positivity still is, is good to have." Stella, individual interview.

By highlighting the benefits of connecting with individuals before their death, the statement emphasises the richness and depth of relationships that can be cultivated through shared experiences and interactions.

5.6.2 Family openness

The challenge of discussing death and dying with family members can reveal the intricate dynamics of familial relationships, emotional vulnerability and existential confrontations within the intimate sphere of personal life. For Dillen, he recalled a conversation he had, not with his family, but about family. The father, who was suffering from MND, could not talk, so his daughter was there. The daughter did not ask her father if she could take time away for a break but asked Dillen instead.

"there's a gentleman there who's He's a lovely guy he's got a great sense of humour. He can't speak, and his daughter was there. Who is basically the same age that I was when my mum was ill and she was, she literally asked me. Could she go on holiday for three days?" Dillen, individual interview.

From this extract, there is an inference that the daughter could not directly ask the father. In addition, when Dillen mentioned that the daughter was his age when his mother had MND, there was a sense of connection and empathy in talking with the daughter. Conversations about death within immediate families can trigger various reactions, from avoidance to deep-seated fears and unresolved issues. These emotions are often heightened within a family setting, making it challenging for individuals to articulate their feelings about life's fragility and the certainty of death.

"So, you absolutely take that opportunity, if you can, and that really upset the gentleman because it was it sort of hit home, and it's that sort of." Dillen, individual interview.

Family ties can be a double-edged sword when discussing various aspects of care. While they can provide support and understanding, they can also serve as obstacles due to past experiences and unspoken assumptions. This can also be seen with Stella when she reveals her experience.

“You know that they are going to be carrying this burden, and, and you know what they're going through is a bigger worry almost than what he is, but his reaction to it was to write big bucket list.” Stella, individual interview.

Compiling a bucket list may symbolise a desire to focus on experiences, goals, or aspirations to navigate or distract from the difficulties those around them face. This narrative points to the complexity of emotional responses to stress and worry, highlighting how individuals may seek solace, purpose, or distraction through activities like creating a bucket list in the face of challenging circumstances. Stuart from the focus group discussed the complex dynamics of assuming leadership responsibilities within the family while still having ageing parents and other family members present.

“That there's definitely something in there isn't that about taking, taking, that leadership responsibility, even while you're still got ageing parents and other family members around you, we don't tend to have these conversations at all.” Stuart, Focus Group.

There is a suggestion that people often refrain from discussing changes in roles and responsibilities within the family, which underlines a tendency to steer clear of conversations. This story emphasises the importance of communication and proactive involvement in handling leadership transitions, caregiving duties, and decision-making processes within the family structure. It also sheds light on the relationship between generations, where younger individuals may take on leadership responsibilities as their older relatives can no longer fulfil traditional roles due to age or incapacity. The role shift means that adult children may be tasked with caregiving or making decisions for their parents while the latter can no longer lead the family unit. This change creates a gap in leadership, necessitating the generation to step into that role despite the presence of their elders.

5.6.3 Negotiating personal experience

The Participants' career choices were driven by a strong desire to help others, and they demonstrated a deep sense of purpose, compassion, and altruism that shaped their professional identities and personal values.

“Thrive on the privilege of being the person to hear them as a stranger as, as an accompaniment accompanist.” Angelica, individual interview.

Angelica conveys a deep appreciation for the privilege of listening to others as a stranger and providing accompaniment. The term "*thrive on the privilege*" suggests a profound sense of honour and responsibility in being entrusted with the stories, emotions, and experiences of others. The role of being an accompanist signifies a supportive presence that walks alongside individuals, offering empathy, understanding, and companionship on their journey. By embracing the role of a supportive listener and companion, individuals can create meaningful and enriching interactions that honour the unique narratives and voices of those they encounter.

Stella, too, feels ‘*privileged*’ to be in her current role. She goes on to talk about a significant transition in her career. She moved from working in an office environment to working with dying people.

“To do a job that is the other end of that spectrum, it's not about volumes it's just about making that very small difference to somebody.” Stef, individual interview.

This innate need to alleviate suffering and create meaningful change highlights a fundamental aspect of Stef’s identity and her wish for fulfilment. She strives to align her work with patient’s values and is passionate about making a difference in the lives of those she looks after. Stef’s dedication to helping others goes beyond her job responsibilities or financial rewards and reflects a profound empathy and interconnectedness with humanity. This altruistic drive has led her to pursue a career focused on service, advocacy, and social good, bringing her a feeling of purpose, fulfilment, and authenticity. However, families can question participants' career choices, signifying a divergence in their perspectives, expectations, and values related to work and personal fulfilment.

“I do get that, as I say, oh that's a strange job, why would you why would you want to do that.” Stef individual interview

Family members may struggle to grasp the significance or purpose of the participants' jobs, leading to confusion, disapproval, or a sense of disconnection in their failure to understand their professional identities. Differences in values, priorities, and goals between participants and their families can create feelings of alienation, judgment, or criticism, impeding effective communication and mutual support when navigating the complexities of professional life within a family dynamic.

Dillen receives affirmation for the job that he does.

“But that's the one time we all come together, and there's normally someone with MND. Comes and gives a bit of a talk. And, and for me that's like what I hear this every day, anyway, but for other people it's like this life-changing, you know. You've reaffirmed. Why, I worked for the charity.” Dillen, individual interview.

The shared experience of coming together as a group, typically where someone affected by Motor Neuron Disease (MND) is giving a talk, holds significant meaning. While Dillen’s message may be familiar to the listener, it can be a transformative and impactful moment for others present. This gathering serves as a reaffirmation of purpose and commitment, especially for those involved in charitable work related to MND. The contrast in reactions highlights the diverse ways individuals perceive and internalise shared experiences.

5.7 Discussion

This section briefly discusses each theme, with Chapter 8 offering an integrated discussion of Chapters 5, 6 and 7, including limitations and implications.

5.7.1 Theme 1: We are all part of the sea

Human emotions are intrinsic to acknowledging vulnerability, the importance of self-care, and emotional genuineness (van Manen, 1998). Being open to expressing and managing emotions with sincerity and self-kindness enables a transformative way of responding to challenges and fostering emotional health. Some participants highlighted the significance of physical sensations, emotional reactions, and self-care routines in promoting emotional well-being and managing difficulties related to discussions about death and dying. Nevertheless, the viewpoints of many of the participants indicated that the broader public struggles to confront the emotions evoked by conversations surrounding death and dying.

Many participants highlighted the role of community in conveying messages about death and dying is essential for fostering understanding, support, and shared meaning. Communities can be a platform for sharing narratives, experiences, and cultural beliefs about death and dying (Hansford et al., 2023). Through these communal discussions and rituals, individuals can make sense of death and dying by drawing on shared values, traditions, and perspectives.

This is one of two themes that particularly resonate with corporeality, one of van Manen's four lifeworld existentials (van Manen, 1998; 2016), discussed in detail in Chapter 8, section 7.1. In brief, corporeality is reflected in the participants' accounts and the wider literature on how we communicate, feel, interact and experience the world, which shapes our conversations surrounding death and dying (Davidov & Russo-Netzer, 2022).

5.7.2 Theme 2: Shifting death and dying conversational perspectives

The stakeholder group deliberated on discussions about death and dying both before and after the COVID-19 pandemic, examining how the pandemic altered perceptions and conversations on the topic. The timing of the pandemic significantly influenced participants' understanding and discourse surrounding death and dying. Prior to the pandemic, end-of-life choices were typically made by individuals facing illness and their families, with funerals serving as communal gatherings. However, amidst the pandemic, healthcare professionals assumed a more prominent role in end-of-life care decisions (De Luca et al., 2023). The stakeholder group's perceptions varied, with some indicating heightened engagement in conversations about death and dying due to COVID-19, while others suggest no increase in such discussions.

This is one of three themes that particularly resonate with temporality. One of the four of van Manen's lifeworld existentials (van Manen, 1998; 2016) and is discussed in detail in Chapter 8, section 5.1. In brief, temporality is reflected in the participants' accounts and the broader literature. Temporality encompasses subjective perceptions of time, including past, present, and future. Feelings can shape one's temporal experience, while time constraints and freedoms also impact emotions and coping mechanisms (Davidov & Russo-Netzer, 2022).

5.7.3 Theme 3: Holding hands with death and dying

The findings highlighted that focusing on positive generativity and legacies can promote feelings of satisfaction and engender hope during the later stages of life and after experiencing loss. The absence of a loved one frequently highlights the profound effects of death, leading to contemplation on the significance of communication, empathy, and body with family and friends before it is too late. The findings are similar to other studies, where experiencing loss has been found to bring about a greater recognition of the importance of relationships, the impact of shared moments and the value of conveying emotions and thoughts to loved ones while they are alive (Jolly et al., 2019; Generous & Kelley, 2020).

This theme resonates with van Manen's (1998; 2016) lifeworld existential of Relationality. This is discussed in detail in Chapter 8, section 9.1. In brief, relationality encompasses social, emotional, and interpersonal connections that shape individuals' sense of self and communication. Relationships influence how we share and create experiences with others (Davidov & Russo-Netzer, 2022).

5.8. Summary

There is a recognition that death is seen as an integral aspect of human life and an understanding that embracing its reality could lead to a more enriched and authentic existence. Participant narratives encompassed personal experiences and perspectives on death and dying and their impact on their identity, relationships, and comprehension of the topic.

Chapter 6 will present findings of the perspectives of individuals who are living with a life-shortening prognosis and their perceptions of conversations about death and dying.

Chapter 6
Individuals living with a life-shortening prognosis

6.1 Introduction

This chapter details the findings from the analysis of a group of individuals living with a life-shortening disease. A comprehensive overview of the findings derived from the individuals living with a life-shortening prognosis group interview analysis is provided. Through detailed presentation and analysis, insights into the participants' perspectives, opinions, and experiences of death and dying conversations are offered. Finally, this chapter seeks to uncover key themes, patterns, and implications to contribute valuable knowledge and understanding to the broader research context.

6.2 Methods summary

Seven participants (four males and three females) aged between 30 and 77, all based in the UK, participated in this study. Five of the participants live with Motor Neurone Disease (MND), and two live with cancer. They were recruited via social media, X. Data collection was undertaken online, and procedures are detailed in Chapter 4, section 4.7. Interviews lasted between twenty-eight minutes and one hour and eight minutes.

Most of the participants in this group were living with Motor Neurone Disease (MND). MND can lead to progressive muscle weakness, loss of motor function, and difficulties with speech and swallowing. These physical limitations can impact participants' ability to communicate verbally and express themselves physically and profoundly impact life experiences. MND can evoke a range of emotions, such as fear, anxiety, grief, and loss. People with MND typically experience emotional distress, uncertainty about their future, and changes in their mental well-being, which can influence their participation in this research (MNDA, 2024). MND impacts social relationships, leading to feelings of isolation, disconnection, and changes in their social roles. This can result in challenges in maintaining social connections, seeking support, and engaging in social activities (MNDA, 2024). MND can significantly impact participants' quality of life, affecting their daily activities, independence, well-being, and family interactions. Daily life revolves around symptom management, accessing healthcare services, and maintaining a sense of autonomy and dignity. Participants may grapple with existential questions, spiritual beliefs, and the meaning of life in the face of a life-shortening illness. Exploring these deeper existential concerns during the interviews while providing valuable insights into participants' experiences and perspectives needed to be approached with compassion and respect for their autonomy and agency and provide appropriate support to facilitate meaningful discussions with participants. A brief outline of each participant is presented below.

Edward: resides in the UK and was a 52-year-old male at the interview and living with MND. Before his diagnosis, he was a company director who is married and has four children. He started working at a young age, and at the bottom of the career ladder, and by his late thirties, he became a director. He is driven, has an infectious joy for life, and believes you must work hard if you want anything. Edward lost most of his mobility, so he uses a motorised chair and has an automated home to make life easier.

Nick: resides in the UK and was 77 years old at the time of the interview. He was living with MND. He has worked various jobs and is now a retired scientist. He has gradually lost his mobility, has no functional use of his arms and is dependent on NIV (non-invasive ventilation) for 23 hours a day. He has a very matter-of-fact attitude and had never considered death and dying conversations and was surprised that other people did.

Audrey: did not give her age and has worked in various roles, with her last job being as a secretary. In her middle age, she became confirmed at the Anglican Church, finding their beliefs congruent with how she lived her life. She had previously rebelled against religion, perceiving most religions were based on a ‘holier than thou’ attitude. She had a long journey to being diagnosed with MND but is trying to be as positive as she can about her situation. She moved in with her son and his family to support her needs.

Derek: At the time of the interview, Derek was a 32-year-old nightclub worker. He lives with his parents, and they supported him through his pancreatic cancer prognosis. He is divorced with a young child. He had a business & finance degree and a secure job. He was practising Muslim and was originally from Africa.

Delia: A 58-year-old woman residing in the UK at the time of the interview. Delia was a counselling therapist. She has lived with MND for a couple of years, which has now affected her voice. She was raised as a Jehovah's Witness, which instilled a fear of death, but she no longer fears death, but more a fear of the actual death process. She has children from a previous marriage.

Sonja: At the interview, Sonja was a 60-year-old social worker living with MND. She is divorced and has two adult children. She currently has one granddaughter and is looking forward to the arrival of her new grandson. She has lived in many different locations but now lives with family who are supporting her with her illness. She has a passion for learning and a positive outlook on life. She is 'living in the moment'.

Charles: was a 30-year-old man at the time of the interview and had breast cancer. He went to university and is currently a software engineer. He has struggled with the diagnosis, particularly as it is not associated with men, and recently had surgery, which did not remove the tumour, and now requires further treatments. He is single, with no children, which he has recently been reflected on.

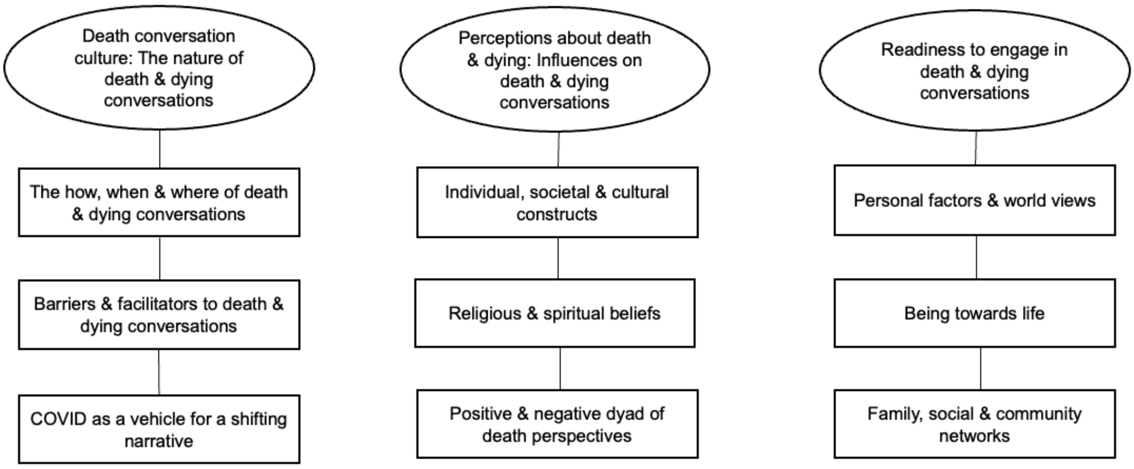
6.3 Findings

Three interconnected themes were derived from the narratives of the participants' accounts. Each of the themes reflected perspectives across all participants' accounts. The first theme: 'Death conversation culture, the nature of death and dying conversations', explores the cultural norms, values, and practices surrounding discussions about death and dying. This theme delves into how societal beliefs, traditions, and taboos shape the nature and dynamics of conversations about death and dying. This theme invites an exploration of the role of family, community, religion, and other cultural factors in shaping the nature and depth of death conversations to uncover the cultural nuances, collective meanings, and shared experiences embedded within the death conversation culture. The second theme: 'Perceptions about death and dying, influences on death and dying conversations, ' focuses on individuals' beliefs, attitudes, and understandings regarding death and dying and how these perceptions shape the way conversations about death unfold. I aimed to uncover the underlying meanings, motivations, and contextual factors contributing to individuals' perceptions about death and dying and their impact on their conversations. This theme offers a deeper understanding of the intricate interplay between personal beliefs, societal influences, and interpersonal dynamics in shaping the discourse surrounding death and dying. The third theme: ‘Readiness to engage in death and dying conversations’, delves into the individual’s emotional, psychological, and interpersonal preparedness to discuss death and dying. I investigated personal experiences, coping mechanisms, cultural influences, communication skills, and past exposure to death and dying discussions that shape individuals’ readiness levels. This theme invites an examination of the emotional barriers, fears or facilitators that influence an individual’s ability to engage in meaningful conversations about death and dying (See Figure 6.3).

Each theme will be described, considering the main aim of the theses. Extracts from the participants’ stories from the interviews will be used to demonstrate the meaning of the themes, enhancing the credibility of interpretations.

Figure 6.3

Presentation of themes and subthemes



6.4 Theme 1: Death conversation culture: The nature of death and dying conversations.

Conversations can incorporate many emotional, social, cultural and existential issues. Conversations can engender fear, grief and sadness, but they may also have a transformative potential, highlighting the importance of engaging in open, frank, and compassionate conversations.

6.4.1 The how, when, and where of death and dying conversations

Most participants had conversations about their illness and death with the health professionals leading up to and following their prognosis. In contrast, most participants did not have open discussions with family members about death or dying despite having a life-shortening prognosis. However, Derek and Audrey's narratives included examples of conversations with family partners. For example, Audrey described her husband as the primary person with whom she would talk about death:

"It's mainly my husband …..and we always, you'd joke about things and say, oh, you're gonna go first. No, you'll be first." Audrey

Audrey indicates a level of trust and emotional closeness in their relationship and shares this light-hearted exchange of joking about who may die away first. This 'banter' may be a coping mechanism to deal with the seriousness and uncertainty of mortality. By engaging in these types of conversations, Audrey and her husband are acknowledging the inevitability of death in a way that is both personal and shared. The humour in their discussion may also serve to alleviate anxiety and create a space for discussing a challenging topic with a degree of camaraderie. Open communication and shared humour in addressing complex subjects like death within relationships are examples of how individuals could navigate existential concerns through connection, shared experiences, and emotional support from loved ones. Derek, in contrast, while he could discuss death with his mother, primarily had conversations about death with his GP:

"maybe my, my, my, GP. For, for him, I, I can, I can tell him anything, because you know he does, he does take care of me when I'm when my condition was so I can tell him what, what I want, what I want my parents to do, and all that. So yeah." Derek

The extract alludes to Derek feeling comfortable sharing his desires and preferences concerning his medical and end-of-life care. This places value on the GP's role in understanding his needs and preferences about decisions regarding his health care. It conveys a sense of trust, comfort, and reliance on the GP as a supportive figure, ensuring that Derek's preferences are respected. Ultimately, this could contribute to a sense of empowerment and peace of mind. However, he said that he could talk openly with his mother.

"With my mum, I am very open with my mum and just talk with anything, so I've talked with her about some issues." Derek

By sharing and talking with his mother, Derek appears to demonstrate a willingness to be vulnerable and seek support and guidance from her. This openness in communication could suggest a sense of security and acceptance within this relationship, allowing Derek to feel he has a safe space to discuss his concerns and seek advice or perspective on his situation.

Some of the participants recalled times when they had talked of death when they were younger. Delia recounted a conversation from her childhood and her initial encounter with the topic of death:

"I remember being 5 and coming out of primary school and dad saying [name] is dead. It didn't mean anything to me." Delia[1]

A five-year-old's innocence and limited life experience may lead to a lack of immediate impact or understanding of death, resulting in a lack of an emotional response. As this is a memory that Delia could recall, it could represent a pivotal moment in her early development of understanding and processing the concept of death. There is likely a gradual and evolving nature of comprehending death and the intricacies accompanying such experiences as a person matures and gains more life experiences. This perspective was further highlighted by Edward, who recalled a conversation with his grandfather when he was nine years old:

"I don't want to die grandad like this, he said, you're not going to die yet Edward, you've got the whole life in front of you." Edward

This extract highlights mortality, resilience and balancing fear and hope, particularly within familial relationships. There is a sense that this was quite a pivotal moment for Edward, as his outlook on life is that of positivity, resilience and making the most of life despite his life-shortening prognosis. He went on to say, *"So where, where in*

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[1] *Delia's husband had to interpret what Delia was saying. MND had affected her speech, which made her difficult to understand via the video conferencing platform

society do we actually talk about death?" suggesting a concern about what are the spaces or contexts in which conversations about death could be encouraged, accepted or normalised. The question raises essential considerations for the need for greater awareness, engagement and supportive discussions about death and dying.

6.4.2 Barriers and facilitators to death and dying conversations

This sub-theme encompasses the factors that can hinder or facilitate discussion surrounding mortality and how or if the COVID-19 pandemic changed death and dying conversations. Derek decided that emotions such as crying, yelling, and fear may surface during death conversations, highlighting the intensity and range of feelings that individuals and their loved ones experience:

> *"Emotions, you know, when you start talking about when you bring up the conversations there are some emotions, that's, that's come out along the way. So sometimes you might cry, sometime people might yell at you, sometimes those around you might cry, might think I'm about to die, they might be afraid." Derek*

Derek's extract alludes to the interpersonal dynamics that can unfold during these conversations, where emotions can unfold and manifest differently. Recognising that those around you may exhibit their emotional reactions emphasises the interconnectedness of emotions within the context of death and dying conversations. This points to acknowledging and navigating these emotions with empathy, understanding and support to foster meaningful and compassionate discussions about the realities of mortality and the human experience, as highlighted in Sonja's conversations with her children and the difficulty of talking to them:

> *"I don't always know exactly where they're at, and I, I think, my frankness and openness about my disease progression. My dying possibility of um assisted dying is quite difficult for them to manage." Sonja*

Sonja's openness and frankness about her disease progression and talk of assisted dying may be a challenge for her loved ones in terms of processing and managing their own emotions and responses to this challenging time. The extract from Sonja alludes to the delicate balance between honesty and sensitivity in communication regarding her wishes. The complexity of navigating conversations about death and dying within the context of family dynamics is acknowledged:

“Everyone seems to be, you know, like afraid to upset people, whereas being upset is part of being human. And it's okay to, you know, and people are afraid of other people's tears, or you know, and yeah, I think we just need to learn to, you know, to move away from that, stop crying to it's okay to cry. And it's okay to be sad, and, you know, and it's okay to talk about how you're feeling.” Sonja

By acknowledging that being emotionally upset is a natural part of the human experience, Sonja appears to challenge the stigma surrounding emotions of sadness by encouraging individuals to recognise and emphasise their feelings without fear of judgment. Sonja seems to advocate normalising crying and emotional vulnerability, highlighting the importance of creating a safe and compassionate space for individuals to share their feelings and experiences openly.

Navigating conversations about death and dying can be complex. Across the participants, there was a suggestion to improve the conversations through education. Delia shared her views about life skills needing to be included in schools:

“Experience of life like life in general about managing your finance….*schools focus on history, geography, or maths, or that …….. it does not teach you the requirements of life like managing a bank account, and living alone, death, credit cards, mortgages, it needs to be incorporated into the system.” Delia*

Delia advocates for a more holistic approach to learning that could incorporate practical knowledge and preparation for the real-world challenges and responsibilities young people will encounter in adulthood. This would include education on death and dying, enabling children to move into adulthood with a better sense of mortality and what it means. Sonja also perceived schools as an ideal environment to help improve the engagement of death and dying conversations:

“In schools acknowledging people's experience, you know, children's experiences of it. I don't know how good schools are now, but certainly, when I was growing up there was definitely no, nothing. Um, I would like to think that there's some kind of improvement.” Sonja

Sonja alludes to a perceived gap or deficiency in how educational institutions historically handled this aspect of life. The desire for some form of improvement suggests a hope for a more compassionate, inclusive and supportive approach to addressing death and grief within the school system. Reflecting on her past could suggest the potential impact of early experiences with death on children’s emotional well-being and the importance of creating safe and nurturing spaces for processing grief and understanding mortality. In addition, Sonja feels that we need to address death and dying proactively and early on.

“We really need to be start to be thinking about this a lot a lot sooner. Be more, more evolved, more prepared, more ready, more able, less afraid I think….it shouldn't be when you're faced with it, that, um, yeah, because that can just make people run and hide can’t it. And that just makes the whole process harder for everyone.” Sonja

By advocating for early learning and preparation, Sonja suggests that being more evolved and ready to face mortality can lead to greater emotional resilience and understanding.

In keeping with the notion of how education can impact our conversational experiences regarding death and dying, Nick shared his exploration of podcasts and how they have affected his understanding and perspective on death.

“I’ve found the world of podcasts and there are some extremely good podcasts about death often by medical professions or counsellors or psychologists or something, and they all paint a peaceful picture of it……… Yes I have and they’ve been fantastic I’ve learnt a lot.
” Nick

The peaceful way death was presented in the podcasts may have helped Nick navigate his thoughts and emotions surrounding mortality, possibly offering a sense of comfort and insight into a universal but often challenging subject. It highlights the possible role of podcasts as a medium and a platform for education, reflection and discussion on mortality. This format could offer individuals opportunities to learn, grow and contemplate the sensitive subject of life and death. He said, *“I think you’ve got to approach from the general to the specific”,* highlighting the importance of a systematic and progressive approach to communication and understanding. Starting with general discussions before moving towards specific details can enhance clarity, engagement and depth of exploration. Delia suggested a way to improve conversations with children by using films, especially cartoon films, to introduce children to the concept of mortality in a way that is accessible, relatable and thought-provoking:

“If it's done to Walt Disney Level, I mean what would you call that...…..there it prepares children for the inevitable….The circle of life was quite good at bringing it into a real into life. I think the the Lion King……But it was one way of bringing the reality of life….and I think it was well put in. It was well aimed at a level that everybody could understand it.” Delia

There is an acknowledgement of the value of using storytelling and visual media to introduce complex themes such as mortality to children and presenting these concepts in an age-appropriate, meaningful and respectful manner. For example, Delia praises how ‘The Lion King’ addresses the circle of life and mortality and the film's ability to spark conversations, promote understanding and provide a framework for exploring life and death with young audiences.

Films are an excellent example of bringing awareness of mortality to children. However, Nick mentioned celebrity role models as a way to bring awareness. He discussed the impact of witnessing public figures raising awareness for Motor Neurone Disease (MND)

"It's nice when we all get a little boost when we see the sports person, when we see them and MND on the news." Nick

Nick appreciates the visibility and attention given to MND when highlighted in news coverage involving sports figures such as Dodie Weir, Rob Burrows, and Rob's friend Kevin Sinfield, all famous rugby players, who stove to raise awareness of MND. Using the words "*little boost*" suggests that seeing sports personalities advocating for MND awareness can evoke feelings of inspiration, unity and encouragement. Nick finds comfort and positivity in the shared acknowledgement of MND through the visibility of these public gifts, indicating a sense of connection and support within the community.

6.4.3 COVID as a vehicle for a shifting narrative

All of the participants in the data set had a life-shortening prognosis when the COVID-19 pandemic emerged in 2020. The pandemic affected the participants in many ways, for example, summarised by Delia, whose quality of life was *'stolen'*:

"It stole your quality of life when she was fit enough to do things, and to sit in the house in quarantine, by the time it lifted she was disabled……..I feel quite resentful of that." Delia

Delia's narrative appears to have a deep sense of loss, frustration, and resentment due to the impact of quarantine measures on her quality of life. The transition from being fit and active to becoming disabled because of the prolonged period of quarantine contributed to the drastic change in Delia's health status and functional abilities, leading to a sense of loss and frustration for her. The resentment may stem from a sense of powerlessness in the face of external factors. This highlights the complex emotions that can arise when witnessing the adverse effects of external circumstances on a loved one's health and quality of life.

However, Audrey had to deal with the death of her husband during the pandemic.

"I suppose different things, it's like, when my husband died, he died in hospital. I Couldn't get to see him, um, I wasn't allowed to see him in the Mortuary or the chapel of rest and on the day." Audrey

The inability to have a final goodbye or to pay respects may have intensified her feelings of loss, helplessness, and emotional pain. The COVID-19 limitations imposed on Audrey's ability to engage in customary mourning rituals or to have a final moment with her husband may have added layers of complexity and emotional weight to the grieving process. Whereas Audrey had to deal with the death of her husband, Sonja felt removed from the risks of COVID-19.

Sonja appears to have a sense of detachment or indifference towards the possibility of dying from COVID-19, suggesting that her current health condition and prognosis overshadow the fear or impact of the pandemic on her view of death.

" Because I got a diagnosis which trumps Covid………..I think I feel quite blasé about, and dying in any other way for me because If that were to happen, then it would probably be, you know, easier than what's ahead of me…………I mean, it might not, I might say, hang on a minute, I want, I want the old card back with the MND cards, you can have this one back, but you know…………..I don't feel that for me personally, um Covid has, has had a huge impact on my view of death and dying" Sonja

The expression of having a diagnosis that "*trumps*" COVID-19 implies that the health condition she is facing carries more weight in her life and outlook on mortality. There is a sense of resignation or acceptance towards the idea of death, with Sonja expressing a willingness to confront the challenges and uncertainties associated with her health condition rather than fearing the potential consequences of COVID-19.

Most of the participants perceived that the COVID-19 pandemic changed the way people thought about and discussed death and dying. Audrey discusses the impact of the pandemic in bringing discussions about mortality to the forefront of people's consciousness.

"Covid bought it all to the forefront because we all had to anticipate that we could get it, and we probably may not come through it. So, I think a lot more people, unless they're burying their heads in the sand, would have discussed it." Audrey

Audrey suggests that unless individuals choose to avoid or deny the reality of the situation, discussions about the risks and potential outcomes of COVID-19 have become more prevalent and necessary to cope with the uncertainties and fears associated with the pandemic. The shared experience of navigating the challenges and anxieties brought about by the global health crisis has prompted a greater willingness among many individuals to engage in conversations about mortality and the existential implications of the pandemic. As Nick said:

“Surely, Covid, which may have been exaggerated in some ways, surely Covid has made people think about death………..maybe we, maybe we should use the pandemic as a way to talk about death.” Nick

By acknowledging the potential exaggerations or sensationalism surrounding COVID-19, Nick highlights the complex and multifaceted nature of public discourse and media coverage during the pandemic. Nick advocates for using the context of the pandemic as a catalyst for initiating conversations about death, highlighting the importance of addressing and normalising discussions about mortality as a means of coping with the uncertainties and fears associated with the global health crisis.

6.5 Theme 2: Perceptions about death and dying: Influences on death and dying conversations

Perceptions of death and dying are complex and sometimes difficult to articulate. Cultural, religious, spiritual and social beliefs may influence how death and dying are understood and approached, impacting end-of-life decisions, grief and mourning rituals. Exploring the participants’ perceptions about death and dying offers insights into the human experience, existential questions, and the interconnectedness of life and mortality.

6.5.1 Individual, societal and cultural perceptions

Funerals are ceremonies after death that honour and celebrate a person's life. They are personal and usually reflect the wishes of the deceased/family. Edward recalled a situation a friend and his daughter had regarding her mother’s funeral. His friend had used direct services for funerals, which did not involve any ceremony. The body is taken to the crematorium, and then the ashes are picked up/delivered to the family.

“A friend of mine's just done that, and she's really regretting it because that was her mum's wishes, and they didn't have a service. And then, her and a daughter are currently having some closure issues with losing their mum and grandmother.” Edward

The regret felt by Edward’s friend suggests a sense of longing for a more traditional mourning process that may have provided her with the opportunity to share in her grief with others, share memories and receive support. Having no service may have deprived Edward's friend and her daughter of the ritualised space for honouring the death of their loved one, connecting with their emotions and finding solace in the company of family and friends. This points to the complex relationship between honouring a loved one and the emotional needs of those left behind to mourn.

In considering the significance of rituals and ceremonies in the grieving process and finding comfort and support in the face of grief, Sonja discussed how, at the age of twelve, she was not allowed to attend her grandmother's funeral. She, at the time, felt it was illogical and exclusionary.

"I was twelve, my granny died. It was my first encounter with death. My granny died when I was twelve. I was not allowed to go to the grave. (to the grave?) Yeah. Went to, went to the funeral, wasn't allowed to go to the grave for whatever reason, and to me as a twelve-year-old, it felt completely illogical……I didn't get a logical explanation, and I felt quite indignant about it. Why was I excluded from this part of um, uh, uh, of the ceremony?" Sonja

There is a sense that Sonja wanted to participate in the funeral ceremony, including the graveside, highlighting the significance of rituals and practices that provide opportunities for closure, remembrance and emotional processing for those grieving a loss. Sonja talked about a funeral she attended as an adult in a different country and how it completely differed from what she had ever experienced.

"The wake is part of celebrating the life. Um, now a wake is before someone is buried where people tend to call the wake here afterwards…... like in the [ ], and people would have, uh, all come together and told stories, and played music, and drunk too much whiskey, and you know, uh, and then come back the next day, and then done the, the final goodbye kind of thing……... basically what I'm saying, and it was, it was, um, it was a very powerful experience, and then at the end of it we had a big party." Sonja

The story highlights the role of the wake as a space for remembrance, reflection and emotional expression. It emphasises the power of a collective experience in honouring the deceased's life, fostering a sense of togetherness and support. She talks about the final goodbye the following day, which signifies the transition from the wake to the formal burial, marking the conclusion of the mourning process and the beginning of the closure for the bereaved. Sonja also talked of a funeral of a fellow MND sufferer as a '*real celebration of life as well."* Edward also revealed an experience of being excluded from a funeral from a young age: *"but I was too young to go to his funeral……...It was not my wish."* From this, there is a sense of disappointment or longing to participate in the funeral service. However, when his mother died, he did not exclude his daughter from the funeral; *"she came to the funeral, so I don't believe in excluding people",* which indicates openness and inclusivity in dealing with loss and grief. By allowing his daughter to be part of the funeral, Edward is acknowledging the importance of involving children in the mourning rituals and providing them with opportunities to understand the process of the concept of death in a supportive environment.

Drawing on several death and dying topics, many participants discussed analogies, legacies, and bucket lists. Delia said death is like falling asleep.

> *"There's the sleep, I've gone to sleep, and I've gone to sleep analogy, but then it may create the fear of going to sleep naturally. It makes it a difficult analogy to use I suppose." Delia*

Drawing on the similarities between the peacefulness of sleep and the idea of a gentle transition into death may complicate the understanding of both concepts for some people. The extract alludes to the importance of sensitivity and awareness in communicating death and dying. Edward likened his illness to a suitcase: *"I imagine it in a suitcase that I carry around with me, and I have to take a suitcase with me."* This statement describes how his illness is carried with him when he goes. It suggests a sense of weight that he must have and that it is a constant daily burden.

Sonja talks about the intention to leave a meaningful legacy for her grandchildren. Creating this book suggests a deep sense of care and consideration for ensuring her identity, values, and life stories are passed down in a tangible and lasting form.

> *"But I have said very specific things around what I'd like to do around my grandchildren, you know, and I'm sure that I, that we get enough photos that we have videos that I'm gonna record some stories, you know. I'm gonna try and put together a book for them about, you know, who I, who I am from my perspective." Sonja*

Recording stories reflects Sonja's commitment to leaving a legacy that provides insight into who she was from her perspective. It is a proactive approach to shaping how her grandchildren will remember her. It highlights a sense of responsibility and love for ensuring that future family members share and cherish her life.

Bucket lists were discussed when thinking about life's purpose and wishes and how they can be part of our legacies. Bucket lists are lists of experiences or achievements a person hopes to have or acquire during their lifetime. Edward talks of a time when someone he knows asked if he had a bucket list following his diagnosis of MND.

“Somebody said to me not long after I got diagnosed have I got a bucket list? And I was like, why would I want a bucket list for, well, so you can go and do all the things you've not done yet………I’d hate to think that somebody's drew, drawn up this list of one hundred things they want to do. Make a cross of ten, and then think that they failed…..I can't think of anything more demotivating than that at all, so I try not to. I try not to get too wrapped up in worrying about what I’ve not done.” Edward

Edward perceives the pressure to check off items on a list as potentially detracting from the present moment and causing unnecessary worry about unfulfilled aspirations. By not dwelling on what he has yet to do and avoiding the creation of a list of goals, Edward adopts a mindset focused on living in the present and appreciating the experiences he has encountered along the way. His resistance alludes to a desire to maintain a sense of freedom, spontaneity and contentment without the burden of predetermined expectations or self-imposed limitations. It highlights Edwards's preference for embracing the present moment and finding fulfilment in everyday experiences rather than fixating on a list of aspirations.

6.5.2 Religious and spiritual beliefs

Spirituality and religion are important for many people in coping, surviving and maintaining well-being. Spirituality is a multifaceted and subjective concept that needs a universally agreed-upon definition, leading to ambiguity in its interpretation. It is an intrinsic aspect of human nature that is intangible and diverse in its manifestations.

“My beliefs belief is when you die, you got the special world spirit world.” Delia

Delia alludes to a sense of comfort, hope, and reassurance in her belief system, offering a perspective extending beyond earthly life and mortality. It emphasises the interconnectedness of life and the possibility of transcending physical limitations. She talked about a friend who went to an angel board reading, and this person’s relative communicated, assuaging her friend’s fear of dying. However, Charles's perspective on faith and death is based on his interpretation of the scriptures.

“When it comes to faith you know when I relate it with death, you know from the scriptures it says written that it is the Almighty God create us and is the one that is capable of our deaths.

So, we don't have any access or any control over our deaths it's all from God almighty." Charles

By attributing the power of life and death solely to God, Charles acknowledges a sense of surrender and acceptance regarding the certainty and uncertainties of life and death. Charles shows a faith-based perspective, which suggests relying on spiritual teachings and scriptures to address existential questions. He finds solace in believing death is part of a larger divine design beyond human comprehension.

However, Derek's experience talks of a fluctuating faith when contemplating mortality.

"I might think of dying next week, but next week comes, and I, I am still surviving, so I can say maybe yeah. My faith keeps on, keeps on fluctuating, fluctuating. Sometimes it becomes sweet, depending on my situation, on the way I am feeling yeah." Derek

There is a suggestion that Derek's faith is not static but responsive to his situation and feelings. This may vary depending on the context of his experiences and how he perceives the challenges of life and mortality. Audrey talked about her experience of being confirmed in the Anglican Church when she was fifty years old and the significance of this experience in her life. *"I don't really know I got confirmed when I was fifty".* She went on to talk about the importance of moral codes and values as guidelines for living.

"But I think the code, the morals are right. It's something to live by…….there's a big social side to that now. It's not like it used to be." Audrey

The enduring relevance of moral codes as a guiding force in life, while also acknowledging the evolving social landscape that influences the interpretation and application of these values, highlights the dynamic nature of ethics and societal norms, pointing to the ongoing importance of moral reflection and adaptation in navigating the complexities of contemporary social environments.

However, Sonja disagreed regarding the priority and importance given to a priest before the family.

"Don't get me, don't get me wrong, uh, the fact that priest always had to be fed first was always, uh, a bone of contention for me when the family should have been fed first." Sonja

The phrase *"the fact that the priest always had to be fed first"* suggests a tradition or custom where the priest is given precedence in receiving food before others. There is a suggestion that indicates a belief that family members should have been prioritised over the priest in matters of serving food, reflecting a value system that emphasises familial care and well-being. The expression *"a bone of contention for me"* conveys Sonja's sense of frustration or disagreement regarding this practice. The discrepancy between the perceived needs of the family and the traditional protocol of feeding the priest first creates a moral dilemma for her, prompting her to question the fairness and ethics of such a custom. This highlights a tension between established practices and personal convictions about justice, fairness and the prioritisation of care within interpersonal relationships. This ties in with Edward's talk about the changing role of religion in modern society, particularly in the younger generations.

> *"Modern society because religion doesn't play so much of a role now in in the younger generations, and I think religion has always the face I mean the whole, the it's a whole promotional offer to the whole population has been join the religion, and you can have a better time in death. No hell for you if you can pray on a Sunday morning. That's always been. That's always been the premise of religion………But nowadays people, you know there's not that role anymore, and we know far more about our own existence………………even the Church has had to bend now with some of its thinking." Edward*

This perspective highlights the historical emphasis within religion on the promise of a positive outcome in the afterlife for those who participate in religious rituals and observances, such as attending Sunday prayers. Edwards suggests a shift in societal attitudes towards religion, noting that younger generations are less inclined to prioritise religious beliefs and practices. He indicates that increased knowledge about the existence and a changing cultural landscape have contributed to a decreased emphasis on traditional religious institutions and doctrines.

6.5.3 Positive and negative dyad of death perspectives

Death can involve fear of the unknown, loss of control, separation from loved ones, or the end-of-life. Negative views may stem from cultural taboos, religious beliefs about punishment, or unresolved issues and regrets. However, death can be viewed in a more positive light, such as death being a natural part of life, a transition to a peaceful state, and a release from suffering. It can be a motivator to live life fully, appreciate life, and foster growth.

Edward talked about a situation with his wife, who was reluctant to seek help or talk about their feelings about Edwards's life-shortening prognosis.

"She doesn't want to talk about it. She, she, she won't, I mean, I tried to organise some counselling, she doesn't want counselling, and I've suggested to go to see Dr X, but she won't go and see Dr X, and suggested she talked to a friend or a sister or somebody, and just, just talk these things through and tell somebody how she feels she's, but she's like, no I'm fine I'm all right, I don't need any help." Edward

The resistance to recognising the need for help may hinder an individual's ability to address the underlying problems. It highlights the intricacies of addressing the challenges of addressing conversations about death and the importance of open communication to overcome barriers by providing space for conversations. For Sonja, she talks about her experience of cultural differences in attitudes towards death and dying.

"I had a huge learning about death and dying when I when I moved away from England, because I think we got a very narrow view, very closed view……just not being so shut off about death, I think, as we tend to be in England" Sonja

Sonja's perspective evolved after moving away from England, giving her a broader and more nuanced understanding of death. She suggests that not being as shut off about death in other cultural contexts implies a sense of greater openness, acceptance or comfort with discussing and acknowledging the reality of death. Nick talks about fear and preferences surrounding the different ways you could die.

"I would have feared dying in a diving accident or dying less than immediately in a car crash, for example, I don't like pain any more than anybody else but if you remove the pain element, I think that's another thing for you to consider whether it's death or the dying process." Nick

There is a suggestion that Nick has an aversion to pain and discomfort, emphasising a common human concern about experiencing suffering in the context of death. By suggesting the removal of the pain element as a separate consideration from death itself, Nick introduces a nuanced perspective on the dying process. This distinction prompts reflection on the significance of pain and suffering in shaping a person's perception of death, highlighting the potential impact of alleviating pain on the overall experience of dying. Consideration needs to be given to the importance of both the event of death and the possible experiences associated with the dying process. Sonja talks of the transformative experience of learning to approach death with openness and acceptance.

“I think it was a real education for me about learning to be more open about it. And you know, feeling that life, death, is part of celebrating life as well……….it's, it's incredibly healthy way. It's much healthier ways than we do generally do here, um, deal with, we deal with death.” Sonja

Sonja alludes to the fact that acknowledging mortality can enhance one's appreciation for the preciousness and beauty of life itself. Her newfound openness to discussing and confronting death represents a departure from societal norms that often avoid or suppress conversations about mortality. This emphasises the value of openness, acceptance, and contemplation of mortality to foster a healthier and more meaningful engagement with the complexities of life and death. Further positive perspectives towards death can be seen by Nick and Sonja as they talked about Death Cafes.

“I realised that many years ago, probably ten years ago, out of curiosity mainly. I, I, I, I attended a Death Café………I wondered whether this is something, consisting of death positivity movement……….I went to about 2 or 3 meetings and the reason I did, it was about that time I just recovered from, from bladder cancer…………I was surprised that people did and went to death café…. Most of the others were, well, over twenty-five, and a lot of young people very dynamic, happy, very bouncy people……they were all very nice, normal people.” Nick

The experience of engaging in discussions about death within a supportive community setting may have provided Nick with a space for reflection, connection, and shared understanding. His observation of the attendees as dynamic, happy, and ordinary people challenges stereotypes about conversations related to death being solely sombre or morbid. It points to recognising the diversity of individuals drawn to discussions about death positivity, the potential for personal growth and reflection following a health challenge, and the sense of community and normalcy that can emerge from engaging in conversations about life's most profound questions. Sonja said, *“It would be a place where I would like to actually go and meet people and talk about it. Um, because I think people are there for all kinds of different reasons, you know, and I think it would be interesting to have that to be, you know, more normal, I suppose”, w*hich echoes Nick’s words. It points to a desire for connection, understanding and normalisation of discussions around mortality, highlighting the potential for personal growth, insight and community engagement through open conversations about mortality. Nick sums up living with a positive perspective *“so you just need to live for a day, a day at a time. So tomorrow will come just like today* *came. It is not half as bad as you thought it might be so, you don't need to bother just like everybody else does….live in the moment."*

Many participants' sense of purpose kept them motivated during tough times. A sense of purpose can increase optimism, resilience, and hope. For Sonja, it was about her work and illness.

> *"I find I spend a lot of time fighting with authorities and fighting for the right thing, which it's a double edged sword, really, because it takes energy…….but it also helps me to feel still significant in the world……..and that I can make a difference." Sonja*

This act of resistance and advocacy can be emotionally and mentally taxing, requiring persistence, courage and dedication to challenging established systems or injustices. Sonja paints the dual nature of advocacy and confrontation with authorities as a "*double-edged sword*." While the process demands energy and effort, it also provides her with a sense of purpose and meaning. There is a sense of reliance, determination and commitment to positively impacting the world. She went on to discuss how her ability to stand up for her beliefs helped her with appointments to get a diagnosis of what was wrong with her.

> *"Well, to me, urgent meant couple of weeks, of course, and, uh, it was dragging on, and maybe me, I'm quite assertive, and I was hounding, uh, the hospital……..as, as a result of my, um, um tenacity. I got a, a cancellation on the eleventh of January, but no preparation for it……..Um, I mean, I'm quite a fighter, anyway, and you may perceive, and also in social work. It's about social injustice." Sonja*

This persistence ultimately produces a favourable outcome, highlighting Sonja's determination and advocacy skills. Her self-identification as a fighter conveys a sense of strength, perseverance, and determination in overcoming obstacles and advocating for justice, particularly in the face of social injustices.

6.6 Theme 3: Readiness to engage in death and dying conversations

The theme of 'readiness to engage in death and dying conversations' encompasses the emotional, psychological, and interpersonal preparedness to discuss death and dying. Participants reflected on their values, prognosis, and relationships and discussed adapting to their new lives.

6.6.1 Personal factors and world views

Participants displayed many characteristics and varying world views that influenced how they reacted to the prognosis of a life-shortening illness. For Audrey, she displayed a fatalistic characteristic.

“I’m a bit of a fatalistic person….I fell on to the scissors into my neck. And Yeh there was nobody up there, my husband was away, and I thought, oh, what have I done? I can't, there's no mirror, can’t see a thing. So, eventually I worked out how to take a photo of my neck and I thought it don’t look too bad. I'll finish watering and then I’ll walk home, have a shower, and go down the hospital if it looks that it's too bad…. When I got to the hospital, she said you were that close, so you probably would have had a couple of minutes and that would have been the end of you.” Audrey

. There is a suggestion that the near-miss incident may evoke a sense of gratitude, introspection, or a reaffirmation of life's fragility and unpredictability. There are several ways that this could be interpreted. For example, it could be seen as a fatalistic perspective on life or as a calm perspective when dealing with dangerous situations. It highlights resilience, resourcefulness, and the profound impact of confronting mortality and vulnerability in moments of crisis. Delia spoke of her way of having to adapt.

“Give you a laugh. I had to take my dressing gown off myself, used the bedside, the bedstead in the bedroom to take it off each shoulder and drop it. You have to have you have to solve problems with different manners, different ways. (Husband said) you're very good at analysing and finding ways round problems and things.” Delia

Using the bedside and bedstead for support, Delia showed a practical and innovative approach to problem-solving. She considered the need to solve problems in various ways, which alludes to a flexible and adaptive mindset when faced with obstacles. Her husband appreciated Delia’s analytical skills and ability to solve challenges. This recognition validates the efforts made and emphasises the importance of having diverse problem-solving skills to deal with various situations effectively.

Some participants believed they wanted to get on with their lives and had to work and get the most out of it.

“I couldn't wait to get out of school, so me and you polar opposites how we approach our careers…….and that's what I ended up doing very early on, and I started the bottom end of my career in retail and spent twenty years working my way through……..by the age of 35-39 I got my first directorship……..then went on to own my own business……..follow my sort of dreams in terms of what I wanted to do…….believed in hard work and that nothing gets given to you and that if you want things, you've got to go and get them.” Edward

By owning his career path and following his aspirations, Edward embodies a sense of agency and autonomy in shaping his professional career. It could be suggested that he shows resilience, ambition, and self-determination around career development. He then talks about his awareness of self and others.

“I know there are people there that are in pain and are suffering and can't cope, and I understand why they would maybe have different attitudes to mine…..But then I think well to spend the next, however many years, feeling sorry for myself, or do I think right? Well, you don't know how long you've got.” Edward

Edward demonstrates a deep sense of empathy and understanding towards differing responses to difficult circumstances. By questioning the value of spending time feeling sorry for oneself versus embracing the uncertainty of life, he exhibits a thoughtful consideration of his mindset and approach to adversity. This contemplation highlights a willingness to confront difficult emotions and choose a path of resilience and acceptance in facing life's uncertainties.

This existential contemplation encapsulates a transformative shift towards embracing life's uncertainties with courage and determination. This highlights the transformative power of empathy, self-reflection, and a mindful approach to navigating life's challenges with grace and resilience. Though he has the resilience to deal with his illness, he spoke about who he was and the issues his illness has caused.

“I mean, I can't use my arms a lot of legs. I rely on other people. But I’m still me. What would I rather? Would I rather be working physically and lose my cognitive ability? No, I think I’ll. I'm quite happy where I, I am. I think if I’ve got to make that choice.” Edward

By expressing a preference for retaining cognitive abilities over physical capabilities, Edward reveals a deep understanding of the significance of cognitive function in shaping his sense of self and identity. This contemplation points to prioritising mental faculties and personal agency over physical independence. Moreover, his assertion of contentment with his current state of being despite physical limitations signifies a profound acceptance and peace with his circumstances.

6.6.2 Being towards life

Participants talked about the symptoms they suffered and how they were mostly ignored. Charles presented with breast cancer symptoms. Delia, Edward, and

Sonja presented with issues with their hands. For Delia, it has progressed to her other arm, her speech, and now her legs, which alludes to the impact on her daily life. Edward had subtle symptoms in his hand and knew that something was not right. Sonja struggled to open jars. She had thought at the beginning that it was age and her strength was diminishing and did not consider it as a symptom of an illness. This alludes to the importance of being attentive to bodily signals and taking early symptoms seriously, even if they may appear minor or inconsequential. Nick suffered from a drop foot and progressed to his legs, and Audrey noticed changes in her legs.

"It started when I first I think I first noticed I wasn't in step, and it was like I was out of step I had to, to think about moving my feet as I was walking……..I just left it, and other little things happened, and I think when, three years later, I um went on holiday with my son and his partner, and my foot was flicking out to the left. Um and they said that you've really got to go back now and see what's going on." Audrey

Audrey spoke of the pivotal moment described during the holiday with her son and his partner, where external observations prompted a reassessment of her symptoms, which signifies a turning point in Audrey's journey towards seeking medical attention. This urging from loved ones highlights the importance of social support and external perspectives in influencing health-seeking behaviours and decision-making processes. The journey from initial self-observation to external acknowledgement and validation emphasises the complex interplay between internal experiences, external feedback, and decision-making processes in navigating health concerns. It alludes to the transformative power of self-awareness, social support, and external validation in shaping individuals' responses to health challenges. Whereas Derek talks of the time when he thought something was wrong.

"It started as a joke, I was feeling some something in my abdomen, and maybe I thought it was just some, some small disease……..it was pancreatic cancer, and it was on on Stage Two." Derek

The abrupt shift in understanding, from perceiving the symptoms as insignificant to receiving a diagnosis of pancreatic cancer at Stage Two, highlights a profound moment of realisation and transformation. This sudden revelation of a serious and life-altering condition signifies a pivotal juncture in Derek's health journey, where the initial dismissal of symptoms gives way to a stark confrontation with a significant medical diagnosis.

Following on from the symptoms that participants dealt with, they discussed how their lives are following the prognosis, showing resilience, acceptance, and adaptive coping strategies. Audrey spoke of how her life has been.

“I've always walked, I've never driven, so, I could walk the seven miles and walk seven back………..it’s been very difficult not knowing what’s wrong, but in some ways I look back and in some ways I was better off not knowing………, but I've got a life in between that, you know, I don't want to be here every day thinking is today the day I'm going to die, and you need to rethink your approach because it's, it's not really right……. You know whether any of my or you got cancer, oh, you've got MND, I didn't cry. I just accepted it. okay, right, how are we going to deal with it……to be as positive as I can, keep yourself as mobile as I can cause I’d rather, eh, as long as I can keep myself mobile and look after myself up to a point.” Audrey

The acknowledgement of potential advantages in not knowing the specifics of her condition suggests a nuanced perspective on the psychological and emotional toll of medical uncertainty. This ambivalence towards knowledge highlights Audrey’s adaptive coping mechanisms and her ability to find a balance between seeking answers and preserving her mental well-being. She contemplates living in the present moment rather than dwelling on the uncertainty of the future, which signifies a profound shift towards positively embracing life. By rejecting a constant preoccupation with mortality and focusing on maintaining a positive outlook and practical strategies for self-care, Audrey demonstrates a profound commitment to living fully and actively engaging with her circumstances. The ‘journey’ from reliance on physical activity to coping with a life-altering diagnosis highlights the transformative power of resilience, acceptance, and adaptive coping strategies in navigating the complexities of living with a life-shortening illness. Sonja believed that the diagnosis was, in some way, a gift.

“I believe in some ways it is a gift……..I know that life is precious, and it means that I need to do everything that I want to do while I can do it, rather than thinking that it's not going to happen to me because it is going to happen to me and um putting life on hold……..I've also got two grandchildren as a consequence, because, whilst my children were both in long term relationships, I, I think that my diagnosis has made them hasten their decision to have children.” Sonja

This reframing of illness as a gift emphasises a deep appreciation for the preciousness of life and a newfound urgency to pursue personal aspirations and experiences while acknowledging the impermanence of existence. By embracing the reality of their diagnosis and using it as a catalyst for proactive decision-making and prioritisation of personal goals, Sonja demonstrates an acute sense of agency and empowerment in navigating her changed circumstances. This proactive approach to life alludes to a transformative shift towards embracing opportunities and experiences with a sense of purpose and intention. Moreover, her reflection on the impact of her diagnosis on her family dynamics, particularly in hastening her children's decisions to have grandchildren, reveals a ripple effect of personal growth and re-evaluation within the familial relationships. The intergenerational consequences of the diagnosis highlight the interconnectedness of individual experiences and the profound influence of personal challenges on family dynamics and decision-making processes. This ripple effect signifies a broader transformation within the family unit, catalysed by the individual's diagnosis and their subsequent re-evaluation of life priorities. Nick also adapted to his life as he feels in a better situation than others.

“You just adapt your life to fit the circumstances………you know, there are people who suffer from terrible cancer, arthritis, you know and not to forget dementia, for example. I’m a dam site better than half of them. So I’m perfectly happy.” Nick

This adaptive mindset highlights a willingness to adjust and find ways to thrive within the constraints of his health challenges, showcasing a sense of agency and resourcefulness in managing his well-being. Adapting life to fit circumstances and expressing gratitude for your well-being amidst comparisons to others facing more severe health issues could provide a sense of resilience, empathy, and perspective-taking. Edward talks of living his life despite his illness:

“I've got an automated home around me……I'm using this mouthpiece here today to use the cursors of my iPad to speak to you…….you can either then hide under the duvet, or you couldn't think right, well okay, I can't drive anymore, or I can still do this I can be driven……. until that point, I was worrying about the gas, the electric and I always worry about, you know Leicester City, who were we going to play at the weekend, and I was worried about when my Simon was coming over for a beer or, what my daughter was needing, you know, next in her next list of demands………We don't live our lives like that. I know some people, like, I'll live for today.” Edward

Edward acknowledges the shift in priorities from mundane concerns to a deeper appreciation for personal relationships and experiences. This shift in focus towards valuing moments with loved ones, living in the present, and embracing life's simplicity suggests a transformation in perspective and a conscious decision to prioritise what truly matters. However, he does acknowledge that it can be challenging.

“It's very easy to, to become a victim, and I think it's very easy to let these things overwhelm you………I'm not saying that I don’t have my bad days, so I do have my bad days……. Sometimes things come along that do, do get you, and we have tears, and I have my angry moments for myself.” Edward

By acknowledging the presence of challenging moments and negative emotions like tears and anger, Edward is willing to confront and process his emotions authentically. This emotional honesty and vulnerability signify a capacity for introspection and emotional expression in response to adversity. Furthermore, Edward’s description of having tears and angry moments for himself alludes to a deep sense of self-compassion and emotional processing in the face of adversity.

Nick talks of his journey of adaptation and resilience in the face of progressive physical limitations due to motor neuron disease (MND).

“I've ended up working for that, but I’ve got to retire pretty soon, because I’ve had MND for seven years, so it's now getting to the point where okay, I can think and talk but I can’t do much else…….About 2 years ago I started non-invasive ventilation………you I am very lucky, I had slow, relatively slow progression MND……Modern technology helps. I am talking to you now and last week a meeting by Zoom……..So I’ve still got a brain, still got a lot of knowledge that I have experienced in my field so you adapt. I can still help. I am still a member of the governing council.” Nick

Nick’s decision to use the non-invasive ventilation two years previously marks a pivotal moment in his journey, highlighting a proactive approach to managing his condition and maintaining his quality of life. Nick’s recognition of being fortunate in experiencing a relatively slow progression of MND speaks to a sense of gratitude and perspective on his circumstances. Nick’s ability to use technology, maintain cognitive abilities, and contribute to his field through participation in the governing council exemplifies a profound commitment to remaining active, connected, and purposeful in the face of adversity.

Participants all talked about their medical journeys. Some had good experiences, but others had bad experiences with health professionals. Derek spoke about the pain and the cost of medical care.

“Feeling that pain I was trying to take some medication, some painkillers but, and it was not going going away, so I decided maybe I should go to the hospital to to get some test…..But after 2 years of medication, I’ve been going for Chemotherapy and these other types of medication I don’t like the…..I got that, you see that, and I had, like, I had very little savings, so I used all my savings to finance my medication.” Derek

Derek discussed his experiences of physical and emotional struggles with illness. The decision to utilise his savings to finance his medication highlights the significant financial burden that comes with managing a chronic illness. The description of enduring pain, seeking medical help, and undergoing treatments like chemotherapy portrays a journey marked by physical discomfort and emotional strain. Despite these difficulties, Derek's willingness to pursue medical interventions and exhaust his savings for treatment highlights a determination to confront the illness and prioritise health.

Edward and Delia had good experiences with the medical profession. Edward talked of the doctor who supported and is still supporting him through his illness. The neurologist provided him with all the information he needed, and a palliative care specialist supported him and explained all his options to him. Delia also had a good experience.

> *GP and he referred me to neurology……he had nerve conduction tests, and that didn't happen until October the 2020……I had really good GP, a very, very good GP and Dr [ ] the consultant, neurology consultant, was absolutely brilliant and very supportive." Delia*

Delia's passage through referrals and diagnostic tests alludes to the complexity and timeline of dealing with the healthcare system to reach a definitive diagnosis. Delia's positive appraisal of her GP as "*really good*" and the neurology consultant as "*absolutely brilliant and very supportive*" highlights the impact of healthcare providers on her healthcare experience. Positive interaction with healthcare providers enhances care confidence and fosters trust, reassurance, and partnership in managing their health concerns. Moreover, Delia's description of the neurology consultant as "*absolutely brilliant and very supportive*" suggests a deep appreciation for the consultant's expertise, empathy, and guidance throughout her healthcare journey. This extract embodies trust, support, and collaboration in navigating the healthcare system and seeking diagnosis and treatment for Delia's health concerns.

However, some of the participants did not have such a good experience. Sonja provides insight into her experience of dealing with the healthcare system.

> *"Eventually, I got for the MRI scan had absolutely no idea what, what was going on. Uh just knew that it was urgent…..So, so, this was October, November. Then I went for a consultation with the registrar, and they said they'd given me absolutely no information. Did some blood. I think they tested for Rheumatoid arthritis, did a few blood tests again, just to exclude other things….and I got a letter saying, well, the good news is It's not your brain. Um, yeah, and it was very noncommittal." Sonja*

This diagnostic experience with blood tests and consultations signifies a period of uncertainty and exploration to identify the underlying health issue. The lack of detailed information provided during the consultation and the noncommittal communication from the healthcare provider contributed to Sonja's sense of ambiguity and lack of clarity regarding her health status. The ambiguity in the communication regarding the MRI results and the exclusion of brain-related issues emphasises the need for empathetic and informative interactions between healthcare providers and patients. This experience of receiving limited information and noncommittal updates may contribute to Sonja's uncertainty, frustration, and the need for more comprehensive and transparent communication in her healthcare journey. It could be seen that the uncertainty and ambiguity show the importance of clear communication in the context of undergoing diagnostic procedures and consultations within the healthcare system. She spoke further regarding the communication she received.

'Would you like the specialist nurse to come in?' and I thought, because I was in the middle of struggling to get my trousers up, that he meant to help me, and I said, No, no, of course, on reflection, I realised that what he should have said was, I think it would be a good idea to get the specialist nursing, because they're very good in these situation…..So, I said no, not realising what his motivation was, his communication skills were shit…….he gave me a prescription for riluzole and said I'll give you this. It won't do you any good." Sonja

The discrepancy between her initial interpretation and the intended message from the consultant highlights the potential for misunderstandings and misinterpretations in clinical interactions. This moment of realisation signifies a shift in Sonja's understanding of the situation and the recognition of the consultant's intention, leading to re-evaluating the communication dynamics at play. This experience of feeling misunderstood and dissatisfied with the communication highlights the need for healthcare providers to prioritise effective communication strategies to enhance patient understanding, trust, and satisfaction. Audrey echoes Sonja's bad experience with the medical profession as she discusses when her symptoms were initially overlooked.

"Yeah, I was making this horrendous cramp and stuff in my leg. So, it was basically ignored…..I was referred to a neurologist, but the wait was really lengthy. Um, nine months or more……..I felt they didn't really bother. But he said, oh, you can, you have another MRI with contrast, and uhm an electrical, I've forgotten what they call it, now something it's electrical. They test each side of your body. (Okay), electrical. And you have all these things stuck over you, yeah, there was a name for it, I think it's set something that was then took

about four hours, and he said, doesn't, you know that there's nothing wrong with you, you're perfect…….does that rule out MND and MS, he said, yes, I'm saying um from that point forward that I think I never saw another neurologist." Audrey

Disregarding symptoms can lead to frustration, neglect, and a sense of not being heard or understood by healthcare providers. The prolonged waiting period may contribute to feelings of distress, uncertainty, and a perception of being overlooked or neglected by the healthcare system. While the clear results may relieve the diagnostic process, the emotional toll of uncertainty and waiting may linger.

6.6.3 Family, social and community networks

All participants talked about their family, friends, and community support. Nick spoke about the Motor Neurone Disease Association forum, a group sharing common experiences living with MND.

"Well, they're, they're a very brave cohort, on the forum." Nick

The characterisation of bravery suggests that the cohort members are actively navigating personal struggles, seeking support, or sharing their stories in a way that inspires admiration or respect. Furthermore, Nick's recognition of the cohort's bravery may indicate an appreciation for the vulnerability, authenticity, and mutual support characterising their interactions within the forum. There is a suggestion of a community within the MNDA. This points to the importance of empathy, understanding, and recognition of the diverse experiences and qualities of individuals who come together in virtual spaces to connect, communicate, and support one another. Audrey also described the supportive services provided by the MNDA, emphasising the positive impact of these resources on her well-being.

"The MND Association send, I have a volunteer come round that I can chat to. I have a free massage once a month and a free aroma therapy once a month, (Nice), Yeah so, but because they've been known to help." Audrey

The presence of a volunteer for chats signifies the importance of social connection and emotional support in the individual's journey with MND. Engaging in conversations with a volunteer provides a space for sharing experiences, concerns, and emotions, fostering a sense of companionship and understanding. This support can alleviate feelings of isolation, offer comfort, and enhance the individual's overall quality of life by facilitating meaningful connections and interactions. The availability of free monthly massages and aromatherapy sessions further illustrates the association's commitment to promoting the individual's physical and emotional well-being.

Derek and Charles discussed family support, whereas Sonja discussed the support she gets from different sources to help manage her symptoms.

“Okay, yeah. I have a friend, I have a friend who does visit me frequently, he’s, he’s an African, but he’s not from my country, he, he’s, he come from a different country, but he is a good friend of mine, so we do relate easily. Me and him, when he is near me, I always feel like I always feel like I’m open, I can just talk anything. So, a conversation like that, yeah, I've talked, I've talked it's to him, he was like he was like encouraging me to, to keep on pushing it. I can just say he's like my mum, so he is quite encouraging.” Derek

Derek’s feeling of being able to talk about anything and express himself openly with his friend points to the importance of having a supportive confidant who offers a safe space for sharing thoughts and feelings. The friend's role in providing encouragement and motivation to Derek reflects a nurturing and positive dynamic in their relationship. He talks of his friend on the same level as his mother in terms of being supportive and encouraging, further emphasising the depth of care, understanding, and emotional support the individual receives from his friend. Charles also found support within his family environment.

“Recently my brother made you know asked to move to my apartment to stay with me to make me to make me as to make me feel happy, sometimes that I may feel sad.” Charles
“December last year, where we were celebrating um the Christmas, mm hmm so we had that in our father's house…..supported that our support that I wasn't abandoned alone.” Charles

The kindness and consideration aim to uplift Charles’ spirits and alleviate feelings of sadness, highlighting the brother's willingness to prioritise Charles’ well-being and emotional health. The gathering and celebration during the holiday season symbolise unity, connection, and solidarity among family members. The support received during this time reminds him that he is not alone in facing challenges or moments of sadness, emphasising the importance of familial bonds and mutual care in providing a sense of belonging and comfort. The acknowledgement of not feeling abandoned alone emphasises the reassurance and comfort derived from the presence and support of family members, especially during festive occasions and times of emotional vulnerability. Charles’ recognition of the family's unwavering support and presence reflects a deep sense of gratitude, security, and emotional connection within the familial relationships. However, Sonja also sought support for symptom management outside the traditional medical settings.

> *“So, I find my support elsewhere, and that is through a nutritionist. I have a herbalist, I see a chiropractor, I see an acupuncturist, I, that's where I find my support, but of course it's, it's very expensive, you know. Um, which makes it difficult.” Sonja*

Sonja seeks to address her physical, emotional, and spiritual needs through complementary and integrative therapies. This proactive engagement with alternative healthcare practitioners suggests autonomy and empowerment in managing her health as she deems appropriate for her beliefs. This financial burden may present obstacles to receiving the desired level of care and support, alluding to the complexities and issues in healthcare access and affordability.

A significant factor for people facing life-shortening illnesses is that of family and how to navigate not only their own emotions but also those of their family. In addition, family dynamics may change as children or partners take on a new role as caregivers. Delia found issues developing with a niece with whom she was very close.

> *“She's got a niece that's very close to her………..her niece, has pulled away from her and it’s very hard for her to cope seeing her aunt like this…………she’s not totally pulled away, she just keeps a distance, so I mean, it’s an emotional distance thing……….She told Delia that she was doing it. She was doing that she couldn't cope with Delia. She loves Delia to bits. We were always very close.” Delia*

The emotional distance maintained by Delia’s niece may serve as a protective measure to manage her feelings of helplessness, sadness, or discomfort in witnessing her aunt's struggles. This emotional distancing can create a sense of conflict between the desire to support Delia and the emotional strain of witnessing her difficulties, leading to a complex interplay of love, care, and self-preservation within the relationship. The niece communicates her struggles to cope with Delia to others, such as expressing her difficulties to Delia herself, which highlights the importance of open and honest conversations in dealing with challenging family dynamics. By sharing her emotional struggles and limitations with Delia, the niece demonstrates vulnerability, honesty, and a desire to communicate her feelings authentically. This communication can foster understanding, empathy, and mutual support within the relationship despite the emotional distance that has been created. The contrast between their previous closeness and the current emotional distance points to the evolving nature of relationships and the challenges that arise when individuals grapple with complex emotions and difficult circumstances within the family context. Not only has Delia’s illness affected her relationship with her niece, but her husband struggled initially. As he was interpreting for Delia during the interview, he spoke of his emotions as he dealt with anticipatory grief in response to Delia's situation. This highlights the complex emotions, uncertainties, and challenges that Delia's husband is facing as he prepares for the future without her. He spoke of not wanting to lose Delia, which reflects a deep sense of attachment, appreciation, and emotional investment in their relationship.

Sonja had to deal with discussions about her death within the family, particularly with her children, for example:

“I’m constantly trying to, particularly my children, I am constantly trying to manage their feelings…..they’re different people to me as well, you know, and it's about respecting their the ability to talk about loss and specifically my death. Sonja

The ongoing effort to address and deal with her children's emotions highlights Sonja’s commitment to providing emotional support, understanding, and guidance in the face of challenging and sensitive topics. Acknowledging the differences in her children's emotional processing and coping mechanisms, she emphasises the importance of respecting and honouring each child's unique perspective, feelings, and ways of expressing emotions. By creating a space for her children to express their thoughts, fears, and questions about loss and mortality, Sonja alludes to a sense of emotional openness, trust, and understanding within the family.

Edward talked of how he wanted his daughter to see him still as a ‘dad’ despite the fact he is immobile and living with MND.

“But, but even now, it's quite important. I don't want Gemma living in her teens dealing with my illness. That's not what I want for her, you know I’m still, dad.” Edward

Edward’s emphasis on wanting to maintain his role as a father despite his illness highlights a commitment to preserving his identity, presence, and connection within the family unit. By asserting his continued role as a parent and caregiver, Edward affirms his ongoing responsibility, love, and support for Gemma, emphasising the importance of maintaining a sense of stability, guidance, and emotional security for his daughter during a challenging time. By recognising the importance of minimising the adverse effects of his illness on Gemma's adolescence, he demonstrates a sensitivity to the complexities of family dynamics, generational relationships, and the need to create a supportive and nurturing environment for his daughter's growth and transition into adulthood. He also revealed how his relationship with his wife had changed. Spoken with much sadness, he revealed what he had lost and wishes he still had with his wife.

It's going to be, we're going to see this through together, and I'll look after you, and I never for what moment imagine I would need carers because I thought, I've got Diane, you know. I just thought we'll be okay…………..I've got a profile bed now, but you can get double profile beds if you Diane wanted one. But there's no intimacy between us anymore………..there's no affection. There's no love and kisses and hugs, and I get hugs and kisses off my friends when I see them." Edward

Despite initially thinking he would rely on Diane for support, Edward's realisation that he would require carers reveals a shift in his expectations, perceptions, and roles within the relationship. Edward talked about the profile bed and how he could get a double bed so that he and his wife could continue sleeping in the same bed, but there is a suggestion that his wife did not want to go that route. The absence of intimate gestures, such as kisses, hugs, and expressions of love, emphasises the emotional distance, loneliness, and loss of connection that can arise within relationships facing health struggles. The expressions of care, dedication, and practical adjustments point to the complexities of love, support, and vulnerability within relationships facing health challenges.

Reflexivity Box

This group of participants, especially those living with MND, challenged me. One participant, in particular, stopped me in my tracks when they said that MND is not the worst disease to have. For me, I have always thought this was a horrible disease, as I have cared for people with MND in the past. Seeing how their body shut down, but they still had all their cognitive abilities, always shook me to my core, and I could not image anything worse. But this participant had said that yes, they could not use their legs or their arms, they were confined to a wheelchair, they needed help with feeding and going to the bathroom, they were still them. They were still the same person. They could still spend time with their family and watch their children grow. They could still live. They felt dementia was worse as the person disappeared along with control of bodily functions. This surprised me and made me reevaluate my view on MND. The participants I spoke to within this section all had a positive attitude and resilience that was so palpable it was humbling. These interviews made me see a different side to living with a life-shortening illness, and because of this, it impacted the way that I interpret the data.

6.7 Discussion

This section will provide a brief discussion on each theme. Participants discussed their death and dying conversational experiences. Their narratives involved their personal experiences and perspectives on mortality and the impact of their life-shortening illness on them and their family. See Chapter 8 for an integrated discussion of Chapters 5, 6 and 7, including limitations and implications.

6.7.1 Theme 1: Death conversation culture: the nature of death and dying conversations

This theme explored the obstacles and enablers of discussion about death and dying, examining how the physical environment affected these conversations and how participants viewed the effects of COVID-19 on altering the dynamics of such discussions. As shown in Figure 6.1, “The how, when, and where of death and dying conversations’ delves into spatial considerations by exploring how the physical setting, timing, and manner in which these dialogues occur can influence the depth, comfort, and effectiveness of communication surrounding death and dying. The spatial context can impact the emotional atmosphere level of disclosure and accessibility of these conversations, shaping participants' overall experience and outcomes. Okken et al. (2012) also found that a larger room size can enhance perceived comfort and the willingness to share personal information.

Findings indicated that although discussing death and dying was seen as a responsibility of the healthcare professionals to start, engaging in these conversations with family members was viewed as intricate and difficult for many. It could be suggested that the environment for having these candid discussions with family members was not consistently established intentionally. A study by Nagelschmidt et al. (2020) outlined emotional, cognitive, communication, relational, and external factors hindering conversations. In addition, the findings emphasised the significance of participants’ childhood discussions about death and dying within various events. Some participants recalled how their caregivers created a safe environment for them to articulate their fears surrounding death. This study reveals that childhood conversations about death are memorable and can influence how comfortable adults feel when engaging in discussions about death and dying. In addition, there is an exploration of how individuals living with a life-shortening prognosis engage in, perceive, and navigate conversations about death and dying. By delving into the nature of death conversation culture, light can be shed on the complexities, diversities, and significances of discussing death and dying within different contexts, offering insights into the broader societal perspectives on death and dying.

This theme resonates with van Manen's (1998; 2016) lifeworld existential of spatiality, discussed in detail in Chapter 8, section 3.1. In brief, spatiality is reflected in the participants' accounts and the wider literature. Spatiality refers to the connection between our surroundings and emotional states; our environment can influence our feelings and perception of that space (Davidov & Russo-Netzer, 2022).

6.7.1 Theme 2: Perceptions about death and dying: Influences on death and dying conversations

Several participants mentioned that they were not present at funerals during childhood and were excluded from significant family gatherings. This exclusion potentially led to feelings of bewilderment and unresolved emotions. One participant decided to let their child attend a family member's funeral, viewing death as a natural part of life and a means to destigmatise the concept. Fristad et al. (2001) propose that children who participate in funerals often find it beneficial in coping with death, particularly when they are actively involved in funeral arrangements.

Many participants viewed religion/spirituality as crucial for providing solace and optimism. Religious practices often offer a structured comprehension of time, death, and the afterlife, providing individuals with a framework to understand their earthly existence and prepare for the transition to the next life (Ando et al., 2010; Harding et al., 2005; Piotrowski et al., 2020). Beliefs in an everlasting soul, diving purpose, or a higher meaning can shape an individual's perception of their approaching death, influence their approach to end-of-life discussions, and help them find significance and comfort when faced with mortality (Jackson et al., 2017; Harding et al., 2005; Piotrowski et al., 2020). Many participants shared their thoughts on religion/spirituality and its impact on their lives. For some, it serves as a source of comfort by offering the belief in an afterlife.

Participants indicated that looking back on their personal experiences, health challenges, and interactions with death and dying could shape their perceptions of a peaceful death, influence their attitudes toward death and dying, and impact how they might express their beliefs, values and preferences. Religion and spiritual convictions serve as a dynamic blend of past, present, and future elements that mould an individual’s response to death and dying. People can blend past encounters and future aspirations into their current perspectives, finding comfort and connection as they approach their final journey.

This is one of three themes that particularly resonated with van Manen’s (1998; 2016) lifeworld existential of temporality, which is discussed in detail in Chapter 8, section 5.2. As Chapter 5, section 5.7.3 mentions, temporality is reflected in the participants’ accounts and the wider literature. Temporality is the subjective perception of time, including past, present, and future, and how these can shape an individual’s experiences (Davidov & Russo-Netzer, 2022).

6.7.1 Theme 3: Readiness to engage in death and dying conversations

The study findings centred on the dynamics of relationships. Emotional connections and evolving family roles in managing life-shortening illnesses. This highlights the significance of understanding and navigating relational aspects during difficult periods. Acknowledging the positive impacts of others underscores the mutual nature of human connections and the significant role of shared experience in cultivating empathy, appreciation, and a deeper understanding of the interconnectedness of lives. Reflecting on the influences of individuals from our past, expressing gratitude for the relationships and memories that have enriched our lives, and fostering a sense of interconnectedness, empathy, and appreciation for human connections can profoundly influence personal development and well-being (Garland et al., 2015; Zhang et al., 2021).

This theme explores individuals' varying willingness, openness, and comfort when conversing about death and dying. There is an exploration of the factors that contribute to individuals' readiness or reluctance to discuss death and dying. The lived experiences, perceptions, and internal processes contributing to individuals' readiness to address death and dying were uncovered. By exploring the readiness to engage in death and dying conversations, I can illuminate the complex interplay of emotions, beliefs, and interpersonal dynamics that influence individuals’ willingness to confront the realities of mortality. This theme offers insights into the cognitive and emotional preparedness individuals bring to death and dying conversations, highlighting the importance of assessing and understanding individuals' varying levels of readiness in navigating conversations about death and dying.

This is one of three themes that resonate with van Manen's (1998; 2016) lifeworld existential of relationality and is discussed in detail in Chapter 8, section 9.2. As mentioned in Chapter 5, section 5.7.3, relationality encompasses social, emotional, and interpersonal connections that can shape an individual's sense of self and how they communicate. These relationships can influence how people share and create experiences with others (Davidov & Russo-Netzer, 2022).

6.8 Summary

Participants discussed their death and dying conversational experiences. Their narratives involved their personal experiences and perspectives on mortality and the impact of their life-shortening illness on them and their family. Chapter 7 will present the perspectives of individuals who are not living with a life-shortening prognosis and their perceptions of death and dying conversations.

Chapter 7
Individuals without a life-shortening prognosis

7.1 Introduction

This chapter details the findings from the third participant data set: individuals not living with a life-shortening disease. By presenting a detailed examination and interpretation of the data, a deeper understanding of the participants' viewpoints, thoughts, and encounters concerning discussions about death and dying is offered. Finally, the significant themes, recurring patterns, and potential implications to enhance the research landscape with valuable insights and knowledge are outlined.

7.2 Methods summary

Seven participants (three male and four female), aged 25-43, were recruited via social media from various backgrounds and occupations. Data was collected online, with the procedures detailed in Chapter 4, section 4.7. The interviews lasted between just over 30 minutes and just over 1 hour.

The age of the participants was considered important, as age is likely to influence perspectives, experiences, and attitudes toward death and dying. Different age groups may have varying cultural norms, beliefs, and experiences related to death and dying. In this study, five participants were in their 20s, one in their 40s and one did not reveal their age. While the aim of the study was not to compare different age groups, it is likely the younger participants approach discussions about death and dying differently from older participants based on generational attitudes, societal influences and life experiences. Participants' age and life stage can shape their views on mortality. Studies reviewed in Chapter 2 suggest younger participants may focus on legacy, future planning, and unfinished goals. In comparison, older participants may reflect on their life experiences, regrets, and acceptance of mortality (Piers et al., 2013. Malcomson & Bisbee, 2009). As discussed in Chapter 2, section 7.2, age can influence communication styles and comfort levels in discussing death. Younger participants may be more open to discussing complex topics, while older people may have accumulated wisdom and insights to share about death and dying (Gutiérrez et al., 2020; Ji et al., 2017). Different age groups may employ varying coping mechanisms when faced with discussions about death. Younger participants may seek peer support or engage in creative expressions, while older participants may rely on spirituality, family connections, or personal reflections (Piers et al., 2013. Malcomson & Bisbee, 2009). I needed to be mindful of the participant's age-related sensitivities, experiences of loss and comfort levels in discussing death and dying. By reflecting on the participants’ age and the implications for the findings, a better understanding of how age influences perspectives on death and dying was gained. Considering age-related factors allowed me to interpret findings nuancedly, recognise diverse experiences across age groups, and provide insights that account for the multifaceted impact of age on participants’ engagement with conversations about death and dying. A brief outline of each participant is presented below.

Debbie: During the interview, Debbie was a 28-year-old female previously working in the healthcare sector. Following an illness, she moved to the finance department of a healthcare firm and gained accounting qualifications. She currently has a hybrid work environment. She had a Christian faith but is now leaning towards atheism and is open to having death-and-dying conversations.

Jane: At the time of the interview, Jane was a 25-year-old PhD student about a year and a half into her program. Jane said she was not religious but liked to think there was some form of afterlife. She sees death as inevitable, not bad.

Ben: Ben was a 43-year-old who worked on people's stories at a charity. He has a degree in Chemistry and likes to think of himself as a rational and logical thinker. He comes from a religious family but is an atheist. He mentioned that he envied those with a belief system that can comfort people in difficult times, but he feels these beliefs do not align with his views.

Ryan: Ryan was a 28-year-old male who is a practising Muslim. He describes himself as modernist and open-minded. He was not clear in what he did for a profession.

Mary: Mary did not give her age but mentioned that she had two grown-up children. She previously worked for a primary care trust and has worked in several jobs within social services. She lived abroad for several years with her husband but returned to the UK due to his ill health. Mary has been the primary carer for her husband for several years. At the time of the interview, her husband was in a care home, and she now was feeling entirely lost, not knowing what to do with herself.

Maria: Maria was a 28-year-old female who was a communications officer at the time of the interview. She lives with her partner and cats and loves to grow vegetables in her garden. She is pretty sporty and loves music and spending time with family and friends. She has an English language and literature degree. In her current role, talking to people who have a life-shortening illness has changed how she thinks, and she is now open to these types of conversations.

Jack: Jack was a 28-year-old trader who was married with children. He lost his job during the pandemic. A Christian, he believed in the afterlife. He found it challenging to start conversations about death and dying because of the emotions attached to the topic.

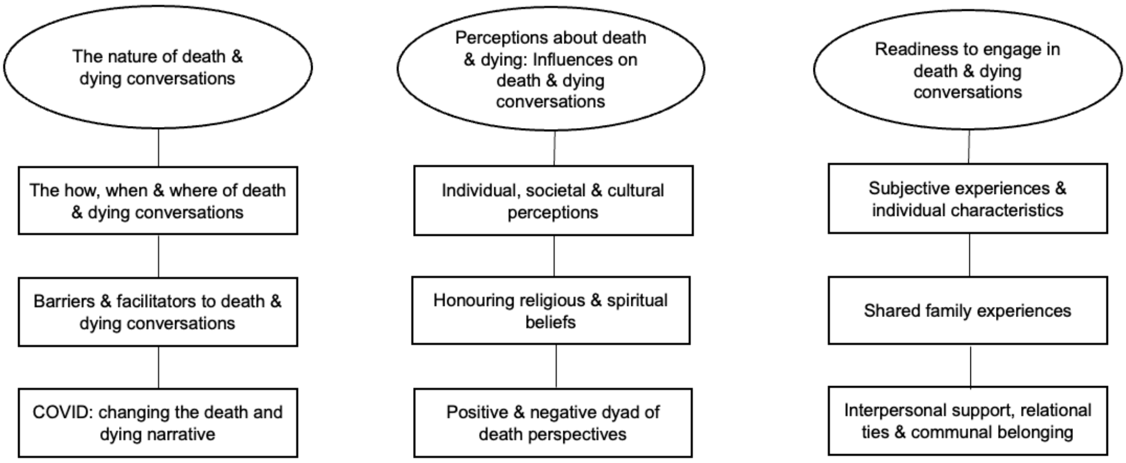
7.3 Findings

Three interconnected themes derived from the participants' narratives are. The first theme is ‘the nature of death and dying conversations’, which delves into the intricate dynamics, nuances, and complexities of discussions surrounding mortality. This theme explores how individuals engage in, perceive, and navigate conversations about death and dying within their personal, social, and cultural contexts. By delving into the nature of these conversations, illumination can be provided on how individuals make sense of death, cope with loss, express their fears and hopes, and seek comfort and connection through dialogue. Insights are offered into the communicative processes, relational aspects, and existential reflections embedded within conversations about death and dying, shedding light on the human experiences and interactions surrounding mortality. The second theme is 'perceptions about death and dying: influences on death and dying conversations’, which delves into individuals’ beliefs, attitudes, and understandings regarding death and dying and how these perceptions shape the nature and dynamics of conversations surrounding mortality. I investigated how personal experiences, cultural backgrounds, religious beliefs, social norms, and past encounters with death influenced their views on mortality. By delving into the influences on death and dying conversations, offering insights into the intricate connections between personal beliefs, societal norms, and interpersonal interactions in shaping the participant's engagement with death and dying conversations. This theme offers a deeper understanding of how diverse influences shape individuals' perspectives on death and dying and informs their conversations surrounding this topic. The third theme is 'readiness to engage in death and dying conversations', which explores the emotional, psychological, and social preparedness to discuss topics related to death and dying. Personal experiences with loss, coping mechanisms, cultural influences, communication skills, and past exposure to discussions about death and dying that shape the individuals' readiness levels were investigated. An examination of the emotional barriers, fears or facilitators that influence individuals' ability to engage in meaningful conversations about mortality was offered. Perceptions and internal processes contribute to individuals' readiness to address death and dying topics. By exploring the readiness to engage in death and dying conversations, illumination can be provided on the complex interplay of emotions, beliefs and interpersonal relationships that impact individuals' readiness to face the realities of mortality. (See Figure 7.3).

Each theme will be described, considering the main aim of the thesis. As in Chapters 5 and 6, anonymised extracts from the participant interviews will be used to illustrate the meaning of these themes to participants, enhancing the credibility of interpretations.

Figure 7.3

Presentation of themes and subthemes



7.4 Theme 1: The nature of death and dying conversations

Similar to participants in data sets 1 and 2, participants in this data set highlighted that discussions about death and the dying process are nuanced and can involve a range of emotional, social, cultural, and existential premises. Emotions evoked typically include feelings of fear, sorrow, and loss, but as previously highlighted, they offer the possibility for transformation and participation in honest, open, and empathetic dialogues.

7.4.1 The how, when and where of death and dying conversations

A range of conversations about death and dying, which occurred at different timeframes across their lives, were shared by the participants, along with avoidance of the topic. For example, Mary shared her inability to have an open discussion with her mother about death, as she appeared to renounce that her mother would die. In contrast, this lack of openness was similarly highlighted by Debbie when describing her grandfather towards the end-of-life:

> *"My grandfather he didn't talk about he didn't have a will in place we didn't talk about his, his funeral arrangements and he knew that he was dying but didn't mention it all to us." Debbie*

Mary and Debbie's narratives highlight how individuals choose not to engage in conversations about it, even when facing their death. Ben described a similar lack of discussion of death with his parents: "*there hasn't been any conversations about what is wanted*". He expanded by explaining that avoidance of conversations about death as he was growing up made this a difficult topic to broach with his parents:

> *"I would say it's something that when I was growing up, death and dying wasn't really massively talked about in the family when there was family bereavements." Ben*

The silence surrounding death within the family may have contributed to a lack of preparation for coping with loss, potentially resulting in difficulties in dealing with grief and understanding the cycle of life and death. Recognising how family communication practises can shape a person's view of death suggests the importance of fostering open and honest conversations about mortality within families. Debbie suggests conversations about mortality could create feelings of sadness or depression, highlighting the discomfort often associated with addressing end-of-life matters:

"It can be rather depressing, can't it uhm. It's not, not everyone wants to talk about that some people are quite private and how they feel and their views on it." Debbie

These participants' examples of responses and attitudes towards discussing death perhaps are a reflection of society in general. In contrast, Ryan outlined that death and dying conversations sporadically arose within his family, typically following a death in the family. Similarly, Jack describes being able to talk to his family but not his friends:

"my dad, my mum, maybe my family, my wife, and my kids can talk to them openly, but my friends is quite complicated. It's a little bit complicated because, you know, I'm afraid of the feedback, so maybe the negative they can start talking negatively so the conversation with my friend I think we just talk about it jokingly, and it's never serious." Jack

Jack appears to 'fear negative feedback' or potential criticism from friends, which highlights the vulnerability inherent in discussing such a sensitive topic. This reluctance to engage in conversations about death with friends reflects the need for safety and acceptance within these relationships. It could be suggested that age may be a factor, as Jack was only 28. However, Jane, who was 25, revealed how death conversations had been integrated as a normal and natural part of family life, suggesting that within her lived experiences, mortality had a sense of acceptance and familiarity: "*it was I know from my experience it was something that was just always normal"*. The normalisation of death conversations could indicate an understanding of the relationship with mortality where discussions about death are not taboo or feared but rather acknowledged as an inevitable part of life. Similarly, Maria recalled a story regarding a friend of the family who had an open conversation with young children about the death of their grandfather:

"their children's grandpa….had died….probably maybe was about five at the time they, they didn't say he went to heaven they didn't say he passed away, they didn't say he went somewhere, they said he has, he has died, and I know through some of the children and young people's information that I wrote that children will just kind of either, not even acknowledge it, or go on about it constantly and say he's died, he's died………and I remember my mum thinking that's not appropriate, that's not appropriate, and I was thinking fair play to her, that's really, really good." Maria

This direct approach contrasts with societal norms of tempering the language used around death. Maria highlighted that her mother found this direct approach welcome, and this endorsement from her mother may have influenced Maria's perception and the way she appeared to value the honesty and clarity used in discussing death with the children. The extract highlights the complexity of how individuals, especially children, process and express their understanding of death and the value of open communication using unambiguous language.

7.4.2 Barriers and facilitators to death and dying conversations

Many of the participants revealed difficulties in having death and dying conversations with family members. For example, Debbie revealed how her grandfather wanted to protect his family from feeling upset discussing his wishes for his death:

"I don't think he wanted us to feel upset, even though we knew we were. It's like protecting those emotions of the ones you love and, that yeah I'd say it's a funny one, isn't it." Debbie

This highlights the complex interplay between emotions, communication and the desire to protect loved ones from any distress. These actions may stem from a sense of care and concern, wanting to spare the family from unnecessary pain or discomfort by attempting to manage or suppress emotions that could be perceived as unfavourable. Debbie's use of "a funny one" points to the nuanced and complicated nature of emotional dynamics within families facing challenging circumstances. There is a suggestion that a deeper exploration of how individuals navigate and interpret the emotional aspects of grief and loss within familial relationships is needed. Debbie expanded further, describing how some people may respond dismissively or shut down conversations about death. Jack also mentioned the challenges associated with discussing death and dying:

"Talking about death and dying, is, it's a very difficult thing because it maybe when you start when you start talking about it, someone can get emotional and maybe start crying So it's difficult talking about it, and it requires some techniques for you to talk about it." Jack

Jack's narrative highlights the impact that discussions about death can have on individuals, evoking strong emotional responses that may manifest as tears or expressions of sorrow. There is a suggestion that discussions about mortality require '*specific techniques'* or approaches to facilitate communication more effectively.

As Jack mentioned, talking about mortality is difficult. Still, for Jane, it was about the unpredictability of life, highlighting the reality that anyone, from a grandparent to a parent or a child, could die unexpectedly at any moment:

“The grandma could literally die tomorrow, and if you've not spoke about already, I mean the mum could die tomorrow the dads, the kid could die tomorrow, and if you're not having that conversation, it just feeds into this fear and I think it is the unknown that scares people.” Jane

The fear of the unknown that Jane alludes to reflects a common human apprehension toward mortality and its uncertainties.

Debbie revealed being open to conversations about death and dying. She mentioned her experience growing up in a family that openly discussed death and mortality from a young age. Her mother initiated conversations about death at an early age, about six or seven years of age, sharing the reality that people die:

“I feel like as a family being quite open about it and that's helped a lot, you know from a young age mum you know we were like six or seven mum would tell us you know one day know people do pass away people do die.” Debbie

The impact of these early conversations implies that open communication about death within the family has been beneficial to Debbie. This highlights the importance of open and honest communication when addressing sensitive topics like death within the family setting. Understanding and accepting the natural process of death can foster a healthy relationship with mortality.

A feature across participants' narratives included ways to improve death and dying conversations. Ben, Jane, Debbie and Maria all suggested using education. Debbie described the lack of education and conversations surrounding death and the ageing process compared to the comprehensive teachings of human physiology, conception, birth and life stages:

“I think about schooling, you know, you get taught about physiology of the human, you know human being yeah conception, the birth, the celebration of birth, the life stages, but and then that’s it really about, you know when you ageing, the ageing process you are not really taught or told about death. And I don't remember being, uhm, I think I had a conversation with my mum about it, you know, you know, thinking as a child, do people actually die? You think they will live forever, don't you.” Debbie

Participants perceived this omission in education to contribute to a sense of denial about mortality with individuals. For example, Debbie revealed, as a child, to struggle to comprehend the concept of death and deal with the idea that people do not live forever. Debbie explained that when she talked to her mother about the reality of death as a child. This emphasises her curiosity and uncertainty about early encounters with mortality. She suggested that as a child, you are naïve about the concept of death. She also remembered that there were no discussions about death at school. By including death education in the school curriculum, individuals may develop the knowledge, skills and resilience needed to deal with the inevitable challenges and transitions associated with mortality in a more informed and compassionate manner. However, Ben, though he advocated for integrating education about death into the school curricula, alludes to the fact that this could be a sensitive topic and evoke societal outcry akin to ‘sex education’ when introduced in the school curriculum. He also mentioned the use of celebrities in social media and the positive impact of these individuals being open and transparent about mortality, illness and the challenges of living with life-shortening illnesses.

“I think people being open and honest about mortality, about illnesses, about battling illnesses about that is a good thing is it Deborah James was obviously recently with the bowel cancer………so things like that, and before that there was uh Steven Sutton, the young chap……..who had big fundraiser um I mean all these people it seems to have big fundraising. So, I think I guess there's anything that makes it more commonplace.” Ben

When individuals feel heard, validated and understood in their struggles, it can create a safe space for them and others to express their emotions and share experiences more openly and authentically. It points to the need to cultivate supportive relationships that encourage honest conversations and reduce the stigma surrounding discussions about death.

Maria suggested the idea of normalising discussions around death and dying as a means of accepting the inevitability of death:

“I think normalising it because it is normal, because it is going to happen, is certainly going to help…….But I just think the more we talk about it, the more it's normalised, the more it's even kind of, I guess, presented in the areas where people are having conversations. So, things like social media, probably the other elements of media that we absorb.” Maria

By presenting death as a natural part of life and encouraging open conversations about it, individuals may foster a culture of acceptance, understanding, and preparedness when addressing end-of-life matters. This highlights the importance of promoting conversations about death to encourage a more open and accepting societal perspective on mortality. Having these open conversations can allow people to be prepared for end-of-life. Jack suggested that discussing death and dying is fundamentally about planning for the future:

"I think talking about death and dying is all about planning, planning for the future, planning for everything. What will happen, what you want to be done, and all that. So it's about. It's all about planning, planning what will happen and what should be done, what I need to be done, and all that." Jack

Jack's perspective highlights the role of planning in dealing with the difficulties of mortality and ensuring that wishes and preferences are honoured. The emphasis on preparing for the future and considering what needs to be done reflects a forward-thinking approach to addressing end-of-life matters. Proactively addressing questions about legacy, medical care references, and funeral arrangements, individuals may be able to alleviate potential burdens on their families, maintain a sense of control over their circumstances, and ensure that their wishes are respected and implemented.

7.4.3 COVID as a vehicle for a shifting narrative

Many of the participants did not have views on whether COVID-19 affected conversations about death. Most perceived that conversations in their world did not change. However, they described how COVID-19 affected them, their families, and society, for example:

"I don't think Covid was a kind of you know, when you're seeing those conversations, and you're watching the news, and somebody talking about the loss of someone who they didn't get to see them, et cetera. ………..it hasn't accelerated any conversations for us. I'd say because we've not been that close." Ben

By acknowledging the impact of not being able to see loved ones, Ben appears to show a sensitivity to the human experiences of separation and loss that have characterised this challenging time. Ben discussed the absence of accelerated conversations about death within his immediate circle due to what he perceived as a lack of closeness with affected individuals. His narrative highlights the importance of relational proximity, shared experiences, and emotional resonance in shaping responses to external events, societal narratives, and collective experiences of loss, separation, and mourning.

Debbie initially revealed the significant numbers of deaths that were provided during COVID; she said, *"so many died today in hospital it's just a number, your given just a number, it's not a single person who died"* suggesting a sense of unease and detachment when faced with impersonal numbers of mortality. She alludes to the need for empathy, compassion and a recognition of the intrinsic value and worth of every life lost, regardless of the scale of the tragedy. However, when asked if COVID had changed conversations about death, she responded, *"not particularly,"* but went on to reveal that people continued with their lives as if the pandemic had been forgotten about: *"people just continuing with their life and it's kind of forgotten about"*. She observed that people lived their lives as before the pandemic, reflecting a collective resilience and adaptability in the face of adversity as individuals strive to move forward and reclaim a sense of stability and continuity in their daily lives. However, in contrast, Jane described being frustrated and conflicted about the restrictions and guidelines imposed during the pandemic:

> *"Annoyed because it's like there were bigger things going on in the world uhm I remember having a lot of conversations about that and I'm very much I stick to the rules as well………if I didn't know, anyone who wants to see a family member when they weren't meant to because they were gonna pass that's their prerogative, I think they were entitled to do that, despite the, what the government was saying. I don't think it was right they have them barriers in place for things that were such significant parts of life, like that." Jane*

Jane's adherence to rules and regulations is juxtaposed with deep empathy and understanding toward those prioritising personal connections and familial bonds over governmental mandates. This moral dilemma highlights the tension between following official guidelines and honouring the need for connection, compassion, and presence during moments of death. Her belief in the importance of allowing individuals to be with their loved ones in times of need reflects a values-based approach to ethical decision-making, emphasising the fundamental rights of individuals to make choices that align with their values and priorities.

Similarly, Maria revealed her experiences during the pandemic and that COVID-19 did not have a direct impact on her:

> *"I'm very, very lucky that it hasn't directly impacted me, but the I think the conversations probably around death have been much more broader so, but I'm quite a political person, so, it was probably centred around that kind of topic rather than specifically death and dying." Maria*

However, Maria alludes to conversations around death have become more commonplace, suggesting a heightened awareness and engagement with existential thoughts brought to the forefront by the pandemic. The broader discussions around death may reflect a collective grappling with mortality, loss, and the fragility of life during this challenging time. This shift in focus towards political discourse may indicate that Maria tends to view and interpret societal issues through a political lens. Her inclination towards political topics suggests a preference for discussing broader systemic issues, policy implications, or societal responses to death and dying rather than focusing on individual experiences or existential reflections regarding the pandemic.

7.5 Theme 2: Perceptions about death and dying: Influences on death and dying conversations

This theme explores how individuals' beliefs, attitudes and cultural perspectives regarding death and dying shape the nature and dynamics of their conversations surrounding this topic. The way an individual perceives death and dying can influence the openness, comfort level, and depth of discussions they engage in about mortality. Cultural norms, personal experiences, and societal beliefs all play a role in shaping these perceptions, impacting the content and outcomes of the conversations about death and dying. Understanding these influences could provide valuable insights into how individuals approach end-of-life discussions, navigate grief, and find meaning in the face of mortality.

7.5.1 Individual, societal and cultural perceptions

Individual, societal and cultural perceptions are the beliefs and values individuals hold. These perceptions encompass personal viewpoints, societal norms, and cultural ideologies that can shape the conversations about death and dying. Individual perceptions can be influenced by personal experiences, upbringing, and individual characteristics, while societal perceptions reflect a community's collective attitudes, values, and behaviours. Cultural perceptions encompass a culture's shared beliefs, traditions, and practices, influencing how individuals within that culture understand and deal with death and dying. Jane discussed societal expectations around ageing and how life fulfilment can contribute to people's fears about dying:

"I think that feeds into the fear that people might have about dying because they feel like, they should reach you know 70, 80 and that they should have had this fulfilled life. You can be fulfilled in your life at any point, from whatever you're doing." Jane

Similarly, Debbie suggests a belief that when you reach a certain age, some people will have achieved a sense of fulfilment in life before facing death. This expectation may create anxiety and pressure for individuals who feel they have not met these perceived milestones, leading to fears and apprehensions about the end-of-life. Debbie expanded her narrative and alluded to fulfilment in life as not solely determined by age or reaching specific milestones. Similarly, Jane suggests that individuals can experience fulfilment at any point in their lives, regardless of their age or stage of development. Framing the concept of life fulfilment as a continuous and evolving process encourages a more flexible and inclusive understanding of what it means to lead a meaningful and satisfying life. Individuals could create a more holistic and appreciative approach to living, allowing them to find purpose, joy and satisfaction in living in the present moment.

For many of the participants, witnessing death can influence how the discussion of death can evolve. Jane talked about the perception of death on TV, her curiosity as a child about death, and the conversation with her mother regarding what death looks like:

“I used to like ask my mum about it what it looks like because, again, in films and TV shows I’d only ever seen, like the really gory like things and she was like it's not like that she's like the just felt like the asleep, which is quite a nice thing to think.” Jane

This excerpt emphasises the influence of media representations on shaping individuals’ perceptions and expectations about death. Contrasting the sensationalised portrayal provided by films and TV shows with the comforting image of death as peaceful sleep given by Jane’s mother points to the importance of personal discussions and lived experiences in shaping and understanding mortality. The picture of death as a gentle and serene process challenges the sensationalised and often fear-inducing portrayals of death in popular media. The serene position of death may offer a more comforting and reassuring view of the end-of-life experience. Jane revealed her experiences of witnessing two types of death: one where she observed her grandmother experience a prolonged dying process, and the second where her other grandmother died quickly.

“Watching her pass for a long time because it wasn't you know the granma that we had grown up with something that was very staged and we knew what they obviously the, the conclusion of it will be.” Jane

Jane's description of '*watching*' her grandmother in the end stages of life over an extended period highlights the complex and emotionally challenging nature of witnessing a person's decline and eventual death. Jane alludes to a sense of acceptance and understanding that comes with bearing witness to her grandmother's slow decline. She revealed the contrasting death of the speed of her other grandmother's death:

"I remember the process and the death that was sudden was a bit more difficult because I didn't understand like you'd hear things about how things happen to them, they but, until it actually happens to you it's a bit difficult." Jane

Confronting the unexpected impact of sudden loss, Jane is faced with the reality of mortality, which can prompt a re-evaluation of perspectives, beliefs, and emotional responses towards death. In contrast, Mary described that following retirement and the decline of her husband's health, she felt disoriented and had a sense of loss of her future and loss of self:

"Everything's upside down, you know, everything. It's not as not, as you imagine retirement to be. You know, it's well, it's not been retirement at all. I mean, only retired in December, but it's, it's just been you know very difficult, a very difficult journey …… And I expect to hear him laughing. And he used to love to go and stand out on the balcony and just, you know, shout at the seagulls and everything else. And I went out the other night about to say, come on. It's about time you were in now. And, of course, he's not well." Mary

Mary's juxtaposition between expectations and reality highlights the struggle to deal with the complexities of the current situation and adjust to the new normal that has emerged. The absence of her husband's presence in these familiar settings accentuates her grief and the profound impact of her husband's declining health.

Several participants mentioned funerals and the rituals associated with death. Jane revealed her experience of dealing with the rituals surrounding death as a teenager.

"It's just odd, it's an odd practice whereas the after do was nice because it's an actual celebration……but that beforehand is just people sat in a room sat together crying uhm which is a bit weird to me like I could be sad on my own, without her being in the room, but not being in the room, do you know I mean…..whole process around that was very different there was no like saying goodbye and stuff like that uhm……so that like I know now that I'm older why, like, I understand now, but then at that age, I was a teenager I was still in high school." Jane

Jane's narrative suggests an individualist approach to grieving and emphasises the need for autonomy in managing emotions and finding solace in different ways.

Jane’s extract highlights the range of responses to death and the importance of acknowledging and respecting individual ways of dealing with the mourning process.

Similarly, Ben shared that he had not attended a funeral until his twenties, and his experiences were drawn from funerals attended by the deaths of his partner's family. He noted that in his partner’s ‘world’, funerals were part of the community, where others would celebrate the dead person's life in the room next to the body, chat and eat and reminisce about the person who died. In addition, he shared an experience of a friend's funeral, which he attended:

“I went to the funeral, and it was standing room only and started with people coming down the middle of the church with, I don't know banners, and almost chanting. It was, you know, very full on……….it was a horrible service in that, you know, the daughter got up and tried to talk about her dad and broke down and had to be helped down, and you know it was very upsetting, but actually having, when they had those modes of the Let us pray, people go to pray.” Ben

Ben mentioned his friend’s daughter’s emotional breakdown whilst trying to talk about her father, highlighting the raw and poignant moments of grief and vulnerability that can arise during funeral services. The daughter's struggle to compose herself and the need for help may have evoked a deep sense of shared sorry and empathy among the people who attended, emphasising the deeply personal and emotional nature of the mourning process. The mention of the prayerful moments during the service alludes to a shift in the atmosphere from intense emotion to a collective moment of reflection, solace and spiritual connection. The act of praying together serves as a unifying and comforting ritual that allows individuals to express their grief, seek solace and find moments of peace and contemplation amidst the emotional intensity of the funeral service. In contrast, Maria offers a unique perspective on mourning and end-of-life celebrations.

“I don't think I would want people to mourn for me, I'd rather have, there are all sorts of things now, aren't there, there are living funerals where, if somebody is terminally ill, they can have a big party or celebration before they die, and they get to be part of it.” Maria

Maria preferred creating meaningful and positive memories with loved ones in a supportive and celebratory environment. This perspective may challenge conventional notions of mourning and highlight the individual's need to shape their end-of-life experiences. By embracing the idea of a living funeral, individuals prioritise connection, celebration and shared experiences over sombre rituals, suggesting a desire for a more life-affirming approach to death and remembrance.

This points to honouring individual wishes and beliefs surrounding death and mourning and acknowledging the potential of celebrating life in the face of mortality.

Across participant's accounts, being prepared or not for the possibility of death was evident. Jane revealed her experience of a meeting with the financial advisor, who, during the meeting, ventured into a discussion about the unpredictability of life and the importance of planning for the future.

“Our financial advisor was like reminding us, she was like it could happen at any time everyone seems to think it's just something that happens when you get to a certain age, but you could literally go out tomorrow and be hit by a bus…..so it's important to make sure things are in place to support loved ones, regardless of your age.” Jane original

This perspective seems to contradict the common belief that events such as death are reserved for older age. This points to the need for preparedness and foresight in ensuring the well-being of loved ones. Jane alludes to the desire to care for and protect loved ones by putting things into place to support and protect them. The extract serves as a reminder of the interconnectedness of life and the importance of taking proactive steps to mitigate potential risks and uncertainties. Encouraging preparedness and planning for the unexpected highlights individuals' responsibilities and commitments towards their families. Being prepared to deal with mortality is seen as important. However, Maria’s narrative is that of being unprepared to face mortality. She spoke of her family’s experience following the death of her grandfather, which offers an insight into the complexities of grief, familial dynamics and emotional expression.

“my grandpa died, and this is almost a real, very real example of how my family worked. He didn't have a will, my dad didn't know what he wants wanted at his funeral, and my dad still to this day has got his ashes somewhere, and never done anything with them. (Wow) So, for me to then be as emotionally open as I am, and my dad to be very much not, I struggled to. I'm going to get upset, sorry.” Maria

There was an absence of a will and clear funeral wishes for Maria’s grandfather, highlighting challenges that can arise when end-of-life decisions are not communicated or planned for. Maria also revealed her contrasting emotional openness with her father's struggle to express emotions, suggesting a divergence in coping styles and communication patterns with the family. This alludes to a potential generational or interpersonal difference in dealing with loss. Maria’s emotional response, expressed through her struggle to maintain her composure during the interview, reveals the depth of her feelings and the personal significance of her grandfather's death. This highlights the importance of clear communication and proactive planning in dealing with the challenges of death and bereavement.

7.5.2 Honouring Religious and spiritual beliefs

As highlighted across participants' accounts, recognising, respecting, and valuing individuals' diverse faith traditions and spiritual practices is essential within society. Honouring religious and spiritual beliefs acknowledges the significance of shaping an individual's worldview, values, and sense of meaning. By honouring these beliefs, individuals and communities can show respect for the sacred, provide space for spiritual expression, and support individuals in practising their faith traditions.

Many of the participants discussed religion and, for some, their religious affiliations. For example, Debbie and Ben declared themselves as atheists. Ben mentioned his family's migration to escape the political turmoil in their home country and his personal experience with atheism, offering an exploration of identity, belief systems, and personal liberations.

> *"My parents left [country] in the early seventies, to get away from the troubles really, which my partner stayed there for a long time, and I would say I had a think awakening is over. They're overstating it, but I found I'm an atheist. I, I, I, found it quite liberating, actually." Ben*

Ben described adopting an atheist position as an "awakening" that signified a transformative moment of self-discovery and intellectual explorations. The shift in belief systems, from previously held devout religious beliefs to atheism, is a significant departure from traditional norms and may symbolise a break from inherited ideologies. His description of finding atheism liberating suggests a sense of empowerment and freedom in embracing a worldview that aligns with his personal convictions and intellectual inquiry. Ben's accounts highlight the dynamic nature of identity formation and belief systems in response to external influences and personal introspection. However, he revealed insights about the value of a belief system*, "I certainly am envious of other people when they have belief systems that give them comfort in difficult times."* There is a suggestion that there is a personal struggle and the search for comfort and support, and his acknowledgement of '*envy*' suggests a recognition of the emotional benefits and coping mechanisms that belief systems can offer in times of distress.

The diverse ways individuals deal with existential uncertainties and seek sources of comfort, and for some through religious belief systems to support to cope with complexities of mortality, emerged from participants' accounts. For example, Jack described his Christian faith and belief in the afterlife, offering an insight into the role of religion in providing comfort, solace and a sense of security in the face of mortality.

"For me. I'm a Christian, and I believe that if I die, maybe I will have a place in heaven. So I'm a Christian, and I'm safe." Jack

When contemplating mortality, believing in divine grace, redemption, and eternal life can offer the individual a sense of security, hope and peace. Jack's assertion that being a Christian makes him feel safe highlights the emotional and psychological benefits that religion can offer individuals in times of existential anxiety and fear. The sense of spiritual security and protection emphasises faith's profound impact in providing comfort, guidance, and resilience in dealing with mortality. However, the most interesting conversation regarding religion was with Ryan. He stated that he was quite religious and that he was a practising Muslim and spoke of the possibility of watching loved ones who had died in his dreams. He described a dream where he met with his deceased uncle and the emotional impact of the encounter, offering an exploration of grief, memory and the human experience of connections across life and death.

"I saw him when I saw him and was able to hold on to most happy to see him, you know, I felt like I felt like I was actually like like I feel again, I knew that he died human, but I remember seeing him I'm trying to see if there's anything else Yes, I suppose I mean, very happy about seeing him…..…and I guess they can made me feel like a, um, there is a link between the world in this life and you know the life after death I guess there has to be some kind of text obviously in the making obviously religious beliefs as well they say that that life after death is just an intermediate stage." Ryan

Ryan talks of a link between the work in this life and the afterlife, suggesting an interconnectedness of existence, memory, and spiritual beliefs. His interpretations of the dream encounter as a glimpse into the continuity of life after death speak to a sense of meaning-making and the enduring nature of relationships beyond this realm. The mention of religious beliefs about life after death as an intermediate stage highlights Ryan’s integration of spiritual perspectives into his understanding of the dream experience. However, Jane, Mary and Debbie state that they were not religious but believed in some form of afterlife. Debbie spoke of the beliefs of others regarding the afterlife, and her perspective as someone without faith offers a nuanced evaluation of existential questions, personal beliefs, the diversity of human experiences, and the interpretations of mortality.

“You know people with their beliefs say think one day, that there could be an afterlife, for you know so for them, that's what they believe in the knowing that that will happen for them…… But for myself right, I don’t have a faith I’d like to think that perhaps it could be something more than, you know, after death.” Debbie

Despite not observing any specific religious doctrine, Debbie’s willingness to entertain the idea of existence beyond death reflects a sense of curiosity and openness to the possibilities of an afterlife. Her mention of the potential for something more after death alludes to a desire for transcendence, meaning, or continuity beyond death.

7.5.3 Positive and negative dyad of death perspectives

This sub-theme encompasses the duality of views and attitudes individuals hold towards death. The positive perspective may involve the idea of death as a natural part of life's cycle, offering comfort, acceptance, and a sense of peace. In contrast, the negative perspective may encompass fear, anxiety, and avoidance of discussions about death, viewing it as a source of pain, loss, and uncertainty. Understanding this dyad of perspectives acknowledges the complexity of human responses to mortality. It highlights the spectrum of emotions and beliefs individuals may hold regarding death, influencing their approach to end-of-life conversations, grief, and existential contemplation.

The majority of individuals tend to have a negative perspective on death and dying. Debbie spoke of the potential for unfulfillment in her life if she were to die at the present moment, which alludes to a deep introspection into her aspirations, regrets, and existential thinking. She talked about life; unfulfillment or lack thereof highlights a fundamental human concern with purpose, achievement, and the realisation of desires and goals. She mentions her best friend, who expressed fear and apprehension towards death.

“I think, at times, just thinking about you know my life, if I were to die right now hasn't been fulfilled……best friends and she's a psychologist and she says how, how frightening she finds death. How, how scary and daunting it is for her.” Debbie

The juxtaposition between Debbie’s contemplation of life fulfilment and her friend's fear of death highlights the complex interplay between personal aspirations, existential fears, and emotional responses to the inevitability of mortality. The contrast in perspectives emphasises the diverse ways individuals deal with thoughts of death, meaning-making, and the search for a sense of fulfilment and purpose in life. Her friend’s expression of finding death scary and daunting reflects a common sentiment rooted in the fear of the unknown, the loss of control, and the cessation of existence. This fear of death can stem from a variety of sources, including cultural beliefs, personal experiences, existential philosophies, and psychological factors that shape individuals' attitudes towards mortality and the afterlife.

Ben spoke of how death can bring out conflicts and tensions within families, providing an insight into the complexities of grief, inheritance and interpersonal dynamics in the fact of loss. At the same time, Debbie spoke on the clinical nature of discussions surrounding death and the reluctance to engage with the topic.

“I think when it comes to that topic, you know, death itself, you know. It becomes a bit clinical doesn't it…People associate it you know, we have all these medical advances we’re living for longer and uhm everything is clinically based you know in hospitals and hospices, and, and outside of those settings people are not talking enough about it are the…. I think that people have lost touch with death as such.” Debbie

The medicalisation of death, particularly within hospital settings, can lead to a distancing from the natural processes of dying, the emotional dimensions of grief, and the existential contemplations surrounding mortality. The critique that people are not talking enough about death outside of clinical settings points to a societal taboo or discomfort surrounding discussions of mortality, dying, and end-of-life care. The reluctance to engage with the topic of death in everyday conversations may stem from cultural norms, fear of mortality, or a lack of spaces for open discussions and reflection on the existential realities of life's finitude. There is a suggestion that people have lost touch with death as a natural and inevitable part of life, which speaks to a broader societal trend towards avoidance, denial, or compartmentalisation of death and dying, pointing to the importance of reconnecting with the reality of mortality, embracing conversations about death, and fostering a more holistic and compassionate approach to end-of-life care, grief, and existential contemplation. However, Maria spoke of her past reluctance to discuss death due to familial attitudes and cultural norms, offering an insight into the influence of family dynamics, societal taboos, and personal perceptions of mortality.

"I used to very much be of the opinion that ah, we don't talk about death, it's morbid, and that's come from kind of how my family approach that whole subject………..They don't, they just don't, and it's very much don't talk about that, it's upsetting, and I was very much of that opinion, you know I'll, I'll worry about it when it happens, or if it's happening to one of my family members." Maria

The avoidance of conversations about death may stem from a desire to shield loved ones from distress, a fear of confronting mortality, or a lack of cultural frameworks for discussing end-of-life matters openly. Maria's admission of aligning with her family's perspective of not addressing the topic of death unless it directly affects them or their loved ones highlights the tendency to prioritise immediate concerns and emotional well-being over any thoughts of mortality and existential uncertainties. This reactive approach to dealing with death, focusing on managing emotions in the face of loss rather than engaging with the topic proactively, reflects a common coping mechanism in response to existential anxieties. Maria's acknowledgement of her past avoidance of discussing death and deferring thoughts about it until it directly impacts her or her family speaks to a broader societal trend of discomfort, denial, or silence surrounding mortality and dying. The reluctance to engage with the topic of death may stem from a combination of cultural conditioning, fear of the unknown, and a lack of support for open conversations and reflection on the inevitability of mortality. It points to the importance of recognising and challenging inherited beliefs, fostering open discussions about death, and embracing a more proactive and reflective approach to engaging with mortality. She went on to talk about the time at the age of 16 when her uncle died. She said, "*I was kind of seen as you're a child; you don't need to worry about this kind of thing."* Maria's memory of being shielded from discussions about her uncle's impending death due to her age highlights the common societal tendency to protect children from the harsh realities of death and dying. Her description of discovering her uncle's death without prior discussion or preparation highlights the suddenness and emotional impact of such an event, mainly when not openly addressed within the family. The lack of communication surrounding her uncle's life-shortening condition and death reflects a cultural reluctance to engage with the topic of death, particularly with younger family members, out of a desire to preserve innocence or shield them from distressing emotions. She also mentioned, *“I don't even know if he used the word he's died, he it would probably, and I could be wrong, but it'd probably be something along the lines of he's gone.”* Maria spoke of the vague language used by her father to convey the news of her uncle's death, possibly using euphemisms like "*he's gone,"* pointing to the linguistic strategies employed to soften the impact of death and make it more palatable for the listener. Euphemistic language can serve as a coping mechanism, allowing for a gentler approach to discussing death. Maria’s uncertainty about the exact wording used by her father to communicate the news of her uncle's death alludes to the fading nature of memory and the emotional weight of past experiences, particularly those involving significant life events such as the death of a loved one. Whereas Ryan talked of death being final, permanent, and unsettling, providing insight into the existential fears, uncertainties and emotional weight associated with death and dying.

“It's kind of a nice, not a very pleasant thing to think about……..just because it's final, you know, final quick, permanent there. And you Yes, it's quite scary as well. It's quite scary…… Once you're, once you once you're dead, it's just you've lost your connection with this world” Ryan

Ryan’s admission that thinking of death is scary reflects a common response rooted in fear of the unknown, the loss of control, and the existential dread associated with mortality. His reflection on the disconnection from the world that occurs upon death emphasises the profound existential implications of mortality, highlighting the nature of death in severing ties with the physical realm and the relationships and experiences that define existence.

Death is not always seen in a negative light. For some, understanding and accepting death can be transformative and allow individuals to grow, create connections with others, and find meaning in their lives. As seen with Ben, he spoke about his gratitude for the time spent with others and the enrichment brought by relationships, offering an insight into the transformative power of connections, experiences, and shared moments in shaping lives and senses of meaning.

“Actually we should be thankful for the time, you know, thankful it's a, there's a word that sounds really just already, and we should be grateful for the time that we've had, and that experience, you know the time that our lives have passed, and we've, you know, had good times or whatever we've known somebody or had our life enriched in some way by the individual in the past.” Ben

Ben’s emphasis on being grateful for the experiences, good times, and enriching encounters with others points to the multifaceted nature of human relationships and how interactions with diverse individuals contribute to personal growth, empathy, and understanding of the world.

Debbie also talked about how open her family was to conversations about death and the inevitability of it, and it should be accepted. She went on to speak of the time she travelled and saw cultural attitudes towards death in Thailand and Asia as a celebration of life, offering insight into how different cultures approach and embrace mortality.

“Traveling across Thailand and Asia people are so open about death there's like a huge celebration of life people, you know, aren't afraid of it in fact they welcome it…….but I think it depends on what like my other my best friends and she's Indian/Asian, born in the UK, but they brought their grandma home in a casket and people would come visit bring food round, uhm you know the house was never empty.” Debbie

Debbie’s description of people in Thailand and Asia being open about death and viewing it as a celebration of life highlights a cultural perspective that values the cyclical nature of existence, the impermanence of life, and the interconnectedness of all living beings. The practice of keeping the house bustling with visitors and nourishment symbolises a collective embrace of grief, remembrance, and solidarity in honouring the deceased and supporting the bereaved family. Her recognition of the house never being empty during the mourning period underscores the cultural emphasis on community, shared rituals, and the importance of collective mourning and remembrance in navigating the complexities of grief and loss. This highlights the importance of cultural context, community support, and shared rituals in shaping understanding of mortality, fostering resilience in the face of loss, and honouring the interconnectedness of life and death as integral aspects of the human experience.

Maria had previously discussed her family’s aversion to discussing death, so she had to find an outlet for these conversations. She used Facebook to initiate open conversations about death and end-of-life preferences during Dying Matters Awareness Week, which offers insight into the power of digital platforms in facilitating discussion, sharing personal stories, and fostering community engagement around death and dying.

“I was like, right, what can I do then? Still Dying Matters Awareness Week, so I put it on my Facebook status, and I wrote a big, long thing, this during matters awareness week, I didn't, I

can't remember exactly what I said, but this is a week to open conversations about this incredibly important thing, I'll start, I want to, I want to be cremated, I want my ashes to either be put into a tree like, you know, with soil to grow a tree, or even put them in a firework, and I'll go out with a bang, and, and, and I put that on Facebook, and I said, and I want my one of my funeral songs to be this: what's yours? And I had somebody that works for a funeral director's comment and said, yes, this is amazing. She then shared her story, and then lots of different people started commenting, and I thought, well, if I'm not going to get it from my family, I'll get it from this kind of wider, extended network of friends and contacts, and it was really interesting to, to see what that people wanted." Maria

By using social media to spark discussions, express her wishes, and invite others to engage in dialogue, Maria demonstrates a responsibility to break taboos, challenge societal norms, and foster a culture of openness, acceptance, and empathy towards death and dying. Her expression of wanting to be cremated and having her ashes used to grow a tree or included in a firework as a way of memorialisation shows her sense of control, independence and imagination in shaping end-of-life traditions but also encourages others to contemplate their desires, beliefs and choices related to death and remembrance. By openly discussing funeral song choices and inviting others to share their own, she has created a space for collective reflection, storytelling, and mutual support in exploring diverse perspectives, traditions, and expressions of grief, remembrance, and celebration. Maria got encouraging responses, interactions and personal anecdotes from friends, acquaintances and even a funeral director. This emphasises the importance of community and relationships in dealing with the challenges of death, grief and mourning.

7.6 Theme 3: Readiness to engage in death and dying conversations

This theme encompasses the individual's preparedness, willingness, and openness to discuss mortality-related topics. It reflects a psychological and emotional readiness to address sensitive and profound aspects of life, such as death, dying, and grief. Being ready for these conversations involves having the necessary emotional resilience, communication skills, and support systems in place to navigate the complexities and uncertainties surrounding death and dying.

7.6.1 Subjective experiences and individual characteristics

This theme embodies the unique perceptions, emotions, and personal qualities that shape an individual's worldview and identity. It encompasses the participant's thoughts, feelings, and interpretations of their surroundings, influenced by past and present experiences, beliefs, and values. In addition, it incorporates traits such as personality, values, beliefs, and cultural background that contribute to the participants' identity and behaviour. Participants highlighted personal issues that would impact their motivation for death and dying conversations. Mary reflected on the emotional and existential limitations and challenges she faced because of mobility issues and their impact on quality of life, relationships and thoughts of death and dying.

"You know some people are lucky that they can get out. They've got the power chairs, and they have still got a bit of no life left in them. They're able to enjoy stuff. But there, [Husband], he could still go out……I can't get him out. It's only if he goes into a home that I would then be able to take him out. No, it's that that's depressing It's that that's worrying. I mean, I know that death is going to be at the end of it. I've no idea when that's going to me, and that's the next two years." Mary

The emotional distress at the prospect of her husband potentially needing to move into a care facility reflects the weight of responsibility and concern for his well-being and quality of life. Mary's contemplation of death as an inevitable outcome adds a layer of existential reflection to her narrative, emphasising the uncertainty and anxiety surrounding the future and the finite nature of life. Her acknowledgement of the temporal nature of life and the looming presence of mortality within the next two years evokes a sense of urgency, fear, and contemplation of life's fragility. Here, insight is gained into Mary's emotional responses to the challenges of caregiving, the complexities of ageing and disability, and the existential contemplation of mortality and the passage of time. It highlights the emotional weight of caring for loved ones with limited mobility, the existential concerns surrounding ageing and mortality, and the profound impact of physical limitations on individuals' sense of autonomy, well-being, and quality of life.

Jane, however, talked of how the different deaths of her grandmother affected her. She spoke of how she is a logical thinker and likes routines and order, providing insight into the role of cognitive processes, emotional responses and meaning in the context of the grief and loss she experienced.

"I'm quite a logical thinker and I like routines with order and stuff like that, so like when my grandma died, it was very order and step-based processes whereas that one wasn't uhm so it took a bit longer to process more than anything." Jane

The absence of clear steps or a structured framework for processing death created a sense of disorientation and prolonged the grieving process for Jane. Her need for order and routine in dealing with emotional experiences highlights the importance of cognitive frameworks in managing complex emotions and life transitions. Her struggle to process the second death suggests that the absence of familiar routines and clear steps may have hindered her ability to deal with and make sense of her emotions effectively. The discrepancy between her preferred logical approach and the unstructured nature of the grieving process in the second death emphasises the impact of cognitive styles on emotional processing and adaptation to loss. This highlights the interplay between cognitive processing, emotional responses, and coping strategies in the context of grief and loss. She discussed her emotional disposition and the contrasting sentimentality within her family.

"I think so I think my mum and dad are more sentimental I'm not a very sentimental person uhm makes you feel a bit creepy and stuff and uhm whereas my family are very sentimental. But they always just talk about as a nice and you know it's just someone going to sleep." Jane

Jane's self-awareness of her emotional tendencies highlights a nuanced understanding of her emotional landscape and family dynamics. Despite the differences in sentimentality, Jane acknowledges the familial tendency towards sentimental expressions, particularly when discussing death. The family's use of euphemisms, such as likening death to someone going to sleep, reflects a shared approach to coping with loss and framing difficult conversations in a comforting and gentle manner. This narrative technique may serve as a coping strategy to soften the emotional impact of discussing mortality within the family.

However, Ben and Maria talked about the impact of their work on them. Maria mentioned her shifting experiences and emotional engagement in her role, highlighting the significance of personal connection and storytelling in her work.

"One of the things I used to really crave and, and not have in my old role at the MND association was face-to-face or personal emotional kind of contact…..this role is one that I used to use personal stories in the leaflets that I used to write, and now I'm kind of collecting them. So, it's, it's a really beautiful, beautiful process. It's also very emotionally draining and upsetting at times, but it's also very, very special as well." Maria

Using personal stories in her current role adds depth and authenticity to Maria's work, allowing for a more intimate and heartfelt connection with the individuals and shared experiences. Collecting personal stories is described as beautiful and emotionally draining, highlighting the complex emotional terrain of engaging with others' narratives of struggle and resilience. Maria's ability to navigate the emotional challenges of her role while finding it special and meaningful speaks to her capacity for empathy, resilience, and appreciation for the transformative power of storytelling and personal connection.

7.6.2 Shared family experiences

Family celebrations, challenges, traditions, and everyday activities impact conversations about death and dying. Ben revealed his father's demeanour during his upbringing, which sheds light on the impact of familiar dynamics, emotional availability and communication patterns within the family unit.

"My father would have been reasonably closed emotionally when I was growing up, and, and, that made use of one of the reasons why these things weren't talked about very much as well, but he was pretty closed…..there wasn't a lot of love in that house. He was growing up, and I think he therefore struggled to be emotionally available, and things um grandchildren have come along, and its completely different ball game." Ben

Ben describes their father as emotionally reserved, contributing to a lack of openness. The emotional void Ben experienced in his upbringing may have shaped his perceptions of love, intimacy, and interpersonal relationships. However, the arrival of grandchildren marks a significant shift in familial dynamics, signalling a departure from the emotional limitations experienced during Ben's upbringing. He contrasts this new chapter with the past, highlighting a transformation in the family environment characterised by emotional openness and a different relational dynamic with the grandchildren. This provides insight into the interplay between generations' patterns, emotional availability, and the evolution of familial relationships over time.

Debbie talked of the family's openness about end-of-life wishes and experiences with death, offering insights into the influence of communication, shared rituals and the negotiation of meaning and connection in the face of mortality.

"My mum said to me about what she like for her funeral my grandma's been quite open about it and I think, as a family as well…..my grandfather died, we were all there in the room, when he passed away. We kind of experience that together." Debbie

This shared experience of being present during a loved one's passing signifies a deep bond and mutual support within the family unit. Her recollection of this poignant moment suggests a profound connection forged through shared grief and the process of saying goodbye as a family. The family's history of openness and shared experiences surrounding death and dying may contribute to a sense of closeness, resilience, and emotional support within the family. Debbie’s thoughts on these familial dynamics highlight the importance of communication, shared rituals, and mutual understanding in navigating the complexities of loss and grief as a cohesive unit and providing insight into familial relationships, values, and shared experiences surrounding death and dying. However, it was a different story for Mary from her family's. Mary talked about her son’s possible move to Portugal during a difficult time for her and her husband. This offers insights into the complexities of emotional responses, relational dynamics, and expectations of familial support during times of adversity.

“But then I don't particularly like to ask, you know, I don't like to just thought it would come natural, you know. And they've been away in Portugal for three weeks. And you know, in the house that we live in. And then it came about from my my son's girlfriend that they're planning to go out to Portugal and live there for a year. And I thought what a dreadful time to leave When your father was ill, you know, so ill you know, I thought you'd be there to support us.” Mary

The timing of the son's departure amplifies Mary’s feelings of vulnerability and the perceived absence of familial support during a critical period. Mary’s disappointment at the perceived lack of presence and support from her son and his girlfriend emphasises the importance of emotional connection and mutual care within the family unit.

7.6.3 Interpersonal support, relational ties and communal belonging

Interpersonal support involves the exchange of empathy, understanding, and assistance among individuals, fostering a sense of emotional security and mutual care. Relational ties are the connections and bonds formed through shared experiences, trust, and communication, which contribute to a sense of intimacy and belonging. Communal belonging is feeling part of a larger social group or community where individuals can find acceptance, commonality, and a shared sense of identity. Mary talks about her relationships with her elderly neighbour and the value of interpersonal connection and communication.

“I've got a neighbour who comes in now and again, but she's 86. And she's okay. But it's not quite the same. You know, she just likes to talk about stuff. And I just happily Listen, it's nice to listen to someone.” Mary

Mary’s willingness to listen attentively to her neighbour’s stories and thoughts reflects a sense of empathy, compassion, and genuine interest in the neighbour's experiences. Listening becomes a source of fulfilment and connection for Mary, emphasising the therapeutic nature of being present and engaged in meaningful conversations with others. Her description of the neighbour's visits as an opportunity to *"talk about stuff"* suggests a casual and light-hearted exchange that holds significance in both their lives. Her openness to listening and the neighbour's sharing stories create mutual support and companionship, creating a sense of emotional connection. Here, insight is gained from the shared experience of communication with people.

Many participants mentioned the sense of community they experienced when dealing with mortality. Ben discussed the death of his mother-in-law and how her death was a community affair.

> *“So, you know, uh, when somebody dies, the body's in state for a couple of nights in their family home. It's an absolute open house. When her mother passed away, her mother passed away at half ten at night. By half ten the next morning every bit of furniture in the house that wasn't, you know, built in had disappeared, and just around the outside of every room was chairs like you from, from the local game Football Club. And there was tea urns brought in from the local [name] club except from the kitchen, and then it just it's just open house. Anybody can drop in from the from the town, and they do drop in. And I mean all through the night.” Ben*

Holding a wake at home reflects a communal approach to grieving and honouring the deceased within a familiar and intimate setting. He recalls how quickly the home was changed into a communal space following the passing of his mother-in-law. Furniture was removed to make space for chairs for visitors. The presence of tea urns from the local club further highlights the communal nature of the gathering, with provisions brought in to accommodate guests throughout the night. The description of the open house atmosphere where anyone from the town is welcome to drop in and pay their respects emphasises the inclusive and supportive nature of the community during times of loss. The continuous stream of visitors throughout the night reflects a shared sense of mourning as community members come together to offer their condolences and support to the bereaved family. This highlights the cultural rituals, communal practices, and shared experiences of grief and remembrance within a community, emphasising the significance of communal support and cultural traditions in dealing with the complexities of death and bereavement. Debbie also spoke of the communal atmosphere of when she worked as a nurse.

> *"I think there was nowhere, where working on wards it was nowhere like it's like a little community you know and, and you bounce off each other, and everyone is so supportive uhm, and I feel like for some people who are having treatment it was their kind of escape you know just focus on themselves." Debbie*

The focus on individual care and attention allows patients to centre themselves and focus on their healing, finding solace and support within the compassionate and understanding atmosphere of the ward. The interconnectedness, empathy, and resilience that can characterise the community within hospital wards highlight the benefits of supportive environments, collaborative teamwork, and patient-centred care.

7.7 Discussion

In revealing their lived experiences of death and dying conversations, participants highlighted the barriers and facilitators, the influences, cultural norms, and societal beliefs that have shaped their views. This section will discuss the themes that evolved from the data and how they link to wider literature that further develops our knowledge and understanding of death and dying conversations.

7.7.1 Theme 1: The nature of death and dying conversations

Participants revealed how their bodily sensations, physical reactions, and instinctive responses influenced their views of mortality, which in turn shaped their view of death and dying conversations. Physical manifestations, such as signs of ageing and illness, can be overlooked, concealed, or sanitised during everyday conversations (Fang, 2024). Participants shared their experiences of being shielded from the emotional aspects of death and dying during childhood, which they attributed to a societal fear of death and dying. Terror Management Theory proposes that interactions with the elderly serve as a reminder of mortality for young individuals, leading to increased death anxiety and potential negative impacts on self-esteem and interpersonal communications (Rababa et al., 2021). Participants noted that discussions about death are considered taboo. The medicalisation of end-of-life care in our society may contribute to the avoidance of conversations surrounding death and dying.

Participants expressed the importance of making discussions about death and dying more commonplace. Normalising these conversations involves acknowledging death as a natural aspect of life (Wilson et al., 2023). Incorporating these discussions into daily dialogues and experiences can help to destigmatise the subject. Participants exemplified this by sharing their childhood conversations with family members. By anchoring discussions about death in the physical realities of existence, individuals can confront the bold aspects of death and dying and the transient nature of life in a more concrete and embodied way.

Chapter 8, section 7.2, discusses in detail one of three themes that resonate with corporeality, one of van Manen's (1998; 2016) lifeworld existentials. Corporeality is evident in both participants and existing literature. It influences our communication, emotions, interactions, and overall perception of the world, shaping our discussions about death and dying (Davidov & Russo-Netzer, 2022).

7.7.2 Theme 2: Perceptions about death and dying: Influences on death and dying conversations

Participants postulated there appears to be a taboo and fear and unease surrounding conversations about death. Consistent with previous research, the realisation of life's brevity and the uncertainty of what comes after death can evoke distress, avoidance, and emotional upheaval (Mohammadpour et al., 2018; Çiftci et al., 2024). This uncertainty may impede an individual's willingness to engage in candid discussions about death and dying. Such conversations can surface unresolved issues, unfulfilled aspirations, or unexpressed emotions for some individuals. Recognising missed opportunities can strain relationships, cause emotional turmoil and hinder one's ability to achieve closure and inner peace National Cancer Institute, 2024; Woźniak & Iżycki, 2014; Macmillan Cancer Support, 2024; 2024a).

Funerals play a crucial role as a meaningful time point that helps individuals navigate their grief, pay tribute to the departed, and discover some sense of significance amidst the loss (ref). Funerals symbolise the shift from life to death, offering a structured context for individuals to recognise the passage of time and the irreversible nature of death (Mitima-Verloop et al., 2019).

This is one of three themes that resonate with van Manen's (01998; 2016) lifworld existential of temporality, which is discussed in detail in Chapter 8, section 8.5.3. In brief, temporality is apparent in participants' stories and the broader research. It involves the personal interpretations of time, encompassing past, present, and future, and how these aspects influence an individual's experiences. (Davidov & Russo-Netzer, 2022).

7.7.3 Theme 3: Readiness to engage in death and dying conversations

Studying how individuals without a terminal illness engage in conversations about death revealed complex interactions between personal beliefs, cultural norms, and social relationships.

The findings highlighted that trust, empathy, and shared understanding within relationships can establish a secure environment for individuals to express their aspirations, apprehensions, and beliefs regarding death and dying. Fundamental questions about life's purpose, legacy, and the continuity of existence after death influence an individual's outlook on mortality (ref). Participants shared how social factors influenced their readiness to broach conversations about death and dying, illustrating how interactions with family, friends, and societal norms can either facilitate or hinder such dialogues. As discussed in Chapter 1, section 1.5, Cultural taboos, the stigma surrounding death, and society's avoidance of end-of-life discussions can contribute to a reluctance to address topics related to death and dying (Pyszczynski et al., 1997; Pyszczynski et al., 2015; Routledge & Vess, 2018). Conversely, supportive social circles, transparent communications, and culturally ingrained practices that respect death can foster positive relationships that allow individuals to articulate their perspectives es and emotions concerning death and dying (Timbers & Hollenberger, 2022; Jackson et al., 2018; Piotrowski et al., 2020; Boles & Jones, 2021).

This is one of three themes that resonate with relationality from van Manen's (1998; 2016) lifeworld existentials and is discussed in detail in Chapter 8, section 9.3. In brief, the subjective understanding of time, encompassing past, present, and future, as seen in the participants' stories and existing research, plays a significant role in shaping individuals' experiences (Davidov & Russo-Netzer, 2022).

7.8 Summary

Participants, in discussing their lived experiences of death and dying conversations, highlighted the barriers and facilitators, the influences, cultural norms, and societal beliefs that have impacted them. Cultural contexts, specifically high-context and low-context cultures, can significantly influence research findings, particularly in studies exploring topics like death and dying. In high-context cultures, communication relies heavily on simple cues, nonverbal gestures, and shared cultural meanings (Chen, 2023). Participants from high-context cultures may prioritise indirect communication, collective perspectives, and cultural norms that emphasise harmony and respect when discussing death and dying. They may emphasise implicit communication, shared values and group harmony, which can influence the depth of emotional expression and openness in discussing death and dying. This can lead to nuanced, layered responses that require careful interpretation to uncover underlying meanings and beliefs about mortality. In low-context cultures, communication tends to be more explicit, direct, and individualist (Chen, 2023). Participants may express their views on death and dying straightforwardly, focusing on personal experiences, rational explanations, and individual autonomy. Research findings from these cultures may highlight individual perspectives, diverse viewpoints, and a preference for clear, concise communication about death and dying. Low-context cultures may prioritise individual autonomy, personal opinions, and direct expression of emotions, leading to varied expressiveness in research participants' narratives. For this study, the participant's narratives were from a low-context cultural perspective.

Understanding these influences could provide valuable insights into how individuals approach death and dying conversations, deal with grief, and find meaning in the face of mortality. Chapter 8 will critically discuss the analysis derived from Chapters 5, 6, and 7 by integrating existing literature, theories, and research presented within this thesis.

Chapter 8
Discussion

"The fear of death follows from the fear of life. A man who lives fully is prepared to die at any time." Mark Twain

8.1 Introduction

This thesis has explored the lived experiences of death and dying conversations from three participant groups: stakeholders within the death positivity movement, adults living with a life-shortening prognosis, and adults not living with a life-shortening prognosis. A comprehensive discussion that builds on the study findings will be offered, drawing on the theoretical frameworks outlined in Chapter 1 and the broader literature presented in Chapter 2. The discussion is structured around van Manen's (1998; 2016) lifeworld existentials to offer a nuanced understanding of the participants' collective lived experiences. The implications of the study's contributions to new knowledge will be highlighted, along with potential policy implications. The strengths and limitations of the methodological approach and methods adopted will be presented, with a critical review of personal biases accounted for during data collection, analysis and interpretation of the findings. A dissemination strategy and potential future research directions are outlined before the conclusion of the thesis.

8.2 van Manen's four lifeworld existentials

The experience of engaging in conversations about death and dying and their relationality extends beyond the mere presence or absence of dialogue (Finlay, 2014). It encompasses the significance of the interactions and contexts in which they occur. The multi-dimensional facets and experiences that shaped participants' perceptions of death and dying conversations were evident across individual and participant groups. For example, early experiences of death, family openness to discussions about death, professed roles, and cultural and spiritual beliefs influence a person's perceptions of death. Rituals and drawing on beliefs about the afterlife can explain how people approach and cope with mortality. Similarly, the psychological and emotional aspects of grief, loss, acceptance, and resilience help our understanding of the complex emotions experienced when facing mortality, including coping strategies and support systems. In drawing on van Manen's four lifeworld existentials (1998; 2016), ‘spatiality’ focuses on how individuals experience and relate to physical spaces in the context of death and dying; ‘temporality’ involves how individuals perceive and experience time, including past, present, and future, in relation to mortality; ‘corporeality’ explores how individuals experience their bodies and the bodies of others in relation to death and dying; and ‘relationality’ examines how relationships and social connections influence individuals experiences of death and dying, These will be used to structure the discussion.

Using van Manen’s existential existentials, I will present a nuanced discussion to understand participants' lived experiences of conversations about death and dying. This approach will facilitate exploring how people talk about death and dying, including shifting spatial contexts, bodily experiences, relational dynamics and temporal considerations in conversions. The lifeworld existentials intersect with the themes relating to death and dying conversations, enabling insights into the multifaceted ways individuals perceive, experience and engage with mortality within personal, social and cultural contexts.

Participant group themes mapped to van Manen’s four lifeworld existentials are presented in Table 8.2

Table 8.2

Participant group themes mapped to van Manen’s four lifeworld existentials

Lifeworld existentials	**Stakeholder group**	**Individuals living with a life-shortening prognosis**	**Individuals without a life-shortening prognosis**
Spatiality (lived space)		Theme 1: Death conversation culture: The nature of death and dying conversations.	
Temporality (lived time)	Theme 2: Shifting Death and Dying Conversational Perspectives	Theme 2: Perceptions about death and dying: Influences on death and dying conversations	Theme 2: Perceptions about death and dying: influences on death and dying conversations
Corporeality (lived body)	Theme 1: We are all part of the sea		Theme 1: The nature of death and dying conversations
Relationality (lived human experience)	Theme 3: Holding hands with death and dying	Theme 3: Readiness to engage in death and dying conversations	Theme 3: Readiness to engage in death and dying

8.3 Spatiality

Spatiality (lived space) is the relationship between our environments and how they shape our emotions; the space we find ourselves in can affect how we feel, affecting our experience of a particular space (Davidov & Russo-Netzer, 2022). The concept of spatiality is reflected in nursing research (Palmér et al., 2023; Wilson et al., 2023; Gonella et al., 2022) and responses to illness (Jessup & Parkinson, 2009; Bhasin & Bharadwaj, 2021; Ahn & Lee, 2023; van Rhyn et al., 2020; Eriksen et al., 2022; Davidov & Russo-Netzer, 2021).

In this study, spatiality can be thought of as how individuals appeared to navigate the physical and emotional spaces where conversations of death and dying occur. Spatiality within the discourse about mortality, death, and dying conversations and settings such as hospitals, hospices, homes, and public spaces have unique symbolic and emotional effects. For instance, in hospital environments, the treatment culture, underpinning philosophies of treatment, and the interventions at the end of life may not align with the patient’s preferences, potentially causing more harm than good (Langton et al., 2014; Juthani-Mehta et al., 2015). Contributions from families and friends about death and dying traditionally were excluded (Kellehear, 2012), which can lead to increased distress for the patient and their loved ones (National Confidential Enquiry into Patient Outcome and Death, 2008; Meier et al., 2010). The hospital environment can influence health professionals' perceptions of death and dying and impact how they engage with patients (Jamshidi et al., 2020). In contrast, hospice environments and underpinning philosophies accept dying as a natural part of life. Hospices are designed to provide comfort and support for those nearing the end of life, impacting treatment cultures and advocating more patient and family involvement and choices about treatment and how care is delivered (Wajid et al., 2021; Currow et al., 2020; Sharafi et al., 2022). Spatiality in relation to death and dying includes personal space, privacy, accessibility to emotional support resources, and space to provide comfort and create opportunities to respect diverse cultural and religious practices, highlighting the complexity between physical spaces and the individual.

While many of the themes from the three participant groups had links to spatiality, one has a particular resonance: Theme 1: death conversation culture: the nature of death and dying conversations from the individuals living with a life-shortening prognosis group, outlined below.

8.3.1 Theme 1: Death conversations culture: the nature of death and dying conversations – Individuals living with a life-shortening prognosis

This theme explored the barriers and facilitators of conversations about death and dying, how spatial context influenced these conversations and participants' perceptions of the impact of COVID-19 in changing the dynamics of conversations about death and dying. As shown in Figure 6.1, the subtheme “the how, when, and where of death and dying conversations relates to spatiality by considering how the physical environment, timing, and manner in which these dialogues take place can impact the depth, comfort level and effectiveness of communication regarding death and dying. The spatial context can influence the emotional tone, disclosure and accessibility of these conversations, shaping the overall experience and outcomes for those involved. Similarly, research by Okken et al. (2012) suggests that a larger room size positively impacts the perceived comfort and willingness to share personal information.

Spatiality, in relation to ‘where’ and ‘who’ conversations about death and dying occurred, represented a moment that allowed such conversations to occur, facilitated by creating a compassionate, meaningful, and supportive environment. By creating spaces designed to be sensitive to the emotional needs of individuals, healthcare providers can facilitate meaningful conversations that promote healing and understanding (Yan et al., 2024). Other studies have found the environment where end-of-life discussions take place can significantly influence their effectiveness (Roxberg et al., 2020; Nordin et al., 2017). Spatiality in the context of conversations about death and dying can be conducive to open and empathetic narratives, providing essential support.

Creating space was an important finding within this study. Where healthcare professionals create a supportive environment and are open to discussing death, listening to participants’ concerns, and creating the physical and emotional space to talk, which is conducive to alleviating fears, promote acceptance of death, and facilitate more meaningful and constructive conversations (e.g. St Michael’s Hospice, 2024; Cynthia Spencer, 2024; Hospice UK, 2024a). Research suggests that during these sensitive discussions, the physical space can shape a person’s sense of safety, respect, and emotional well-being (Brown & Di Lallo, 2020; Naseem et al., 2020; Austin et al., 2020). Having a space where individuals feel heard, valued, and respected for their beliefs and values surrounding a death can provide a sense of comfort and relief (Too et al., 2015; Wajid et al., 2021).

Findings suggested that whilst having conversations about death and dying was perceived as one of the roles of health professionals to initiate, conversations with family members were deemed as complex and, for many, challenging. It could be postulated that the ‘space’ to have these open conversations with family was not always created purposefully. A review by Nagelschmidt et al. (2020) identified emotional, cognitive, communication, relational and external factors that inhibited end-of-life discussions.

Discussing death and dying, or to be more accurate, not discussing death and dying, appears to be a behavioural norm rooted in childhood and how ‘the family’ respond to death (Rosengreen et al., 2014). Spatiality in childhood conversations about death and dying is the physical environment where these discussions take place. Creating safe, comfortable, and age-appropriate spaces is crucial for supporting children in understanding and coping with death and dying (Dignity in Dying, 2024). The spatial context can impact the emotional tone of conversations and influence how children engage with and process the complexities of death and dying. By recognising the significance of spatiality in these conversations, families, caregivers, and professionals can create environments that facilitate open, honest, and supportive dialogues to help children navigate these challenging topics (Hospice UK, 2024).

Age and spatiality can play significant roles in how individuals engage in conversations about death and dying. The study findings highlighted participants' experiences of conversations about death and dying across groups in childhood were important. For some, their caregivers provided a physical and emotional space for them to express their fears about death. Safe spaces seemed to help normalise and accept death and dying as part of life. However, consideration must be given to the child's cognitive abilities, and conversations must be introduced in an age-appropriate manner.

Understanding of death evolves as children mature. Typically, under the age of five, death is perceived as a state of long sleep (Ji et al., 2017; Wong, 2019;

Bering & Bjorklund, 2004; Subbotsky, 2020; Brent et al., 1996). Older children may be able to grasp the finality of death from about the age of 8 years and can begin to understand the permanence of death (Stylianou & Zembylas, 2018). However, parents/caregivers may feel they need to protect their children from the pain and fear of death and avoid having these conversations (Mahon et al., 1999; Papadatou et al., 2002). Research suggests that avoiding open discussions about death can have a detrimental effect on the child's development in that they are unprepared for dealing with the death of a loved one, creating mental health issues or increased separation anxiety (Dowdney, 2008; Branch & Brinson, 2007). Leaving a child alone with their fears and misunderstandings could lead to these fears increasing, leading to guilt, isolation and possible future mental health issues.

Adolescents may face death within their peer group or family, which could bring up existential questions about death, such as what control they have over life, what is the meaning of their life and is there life after death. Providing space for adolescents is needed to respect their autonomy, offer opportunities for reflection, and express their emotions. Space can reduce stress, increase positive moods and lower psychological distress (Tillmann et al., 2018; Zhang et al., 2020; Vanaken & Danckaerts, 2028; Testoni et al., 2021a). The current study sheds light on the fact that childhood conversations are remembered and can be reflected tangibly as relevant to how, as adults, we feel comfortable or not in having death and dying conversations.

Adults approach conversations about death with a broader range of life experiences, personal beliefs, and experiences of death. They may consider end-of-life planning, legacy and the impact of their mortality on loved ones (Schiltz et al., 2014; Llewellyn et al., 2017; Gjerber et al., 2015). Studies have found that adults benefit from having a private space for conversations about death and dying, allowing reflection, connecting with loved ones and access to resources that help navigate discussions and decision-making. As with adolescents, adults' mental well-being can benefit from having a space; Gallant et al.'s (2020) literature review explored leisure as a tool to create change for the social inclusion of people with mental health issues. From the review findings, they created guidelines to support recreational venues to find spaces to build relationships, collaborations, peer support, and supporting people to talk about issues that are important to them. Though this study focussed on mental health, the findings can be extrapolated to the creation of spaces to have conversations about death and dying. These guidelines would help in creating a space that can foster engagement, competence and confidence in dealing with the topic of death and dying.

Older adults may confront conversations about death and dying more directly as they face health challenges, the death of peers and end-of-life decisions. Sridevi and Swathi (2014) found that institutionalised and non-institutionalised older adults reflected on their life legacy and preparation for the end-of-life and had increased death anxiety. Carr & Fang (2021) interviewed independent older adults with an average age of 79 years and found they feared being abandoned and forgotten and that they did not matter, leading to existential loneliness. A space to talk about their lives that is accessible and comfortable could be invaluable in offering opportunities for social connections.

In this study, spatially was alluded to in other themes: Theme 2: Shifting death and dying conversational perspectives – stakeholders and Theme 1: The nature of death and dying conversations – individuals without a life-shortening prognosis. Participants perceived that including death education in the curriculum at different time points and providing space to discuss death and dying would increase awareness, knowledge, and understanding of death-related topics, help individuals develop coping skills, and enhance communication (King-McKenzie, 2011; Kellehear, 2012; Kellehear, 2014a). Death education should include the social, psychological, cultural, spiritual and ethical aspects of mortality, end-of-life care, and advanced planning (Kastenbaum & Moreman, 2024). Education should be age-appropriate and integrated into the school curriculum, professional training programmes, community workshops and public awareness campaigns (King-McKenzie, 2011; Schiltz et al., 2014; Ellison & Radecke, 2005; Thornton, 1991; Tieman et al., 2018 and Li et al. 2023). The benefits of engaging in death education include preparing for a good death and afterlife (Liu & van Schalkwyk, 2018) reduce fear and anxiety (Lockhart et al., 2001; Mohammadpour et al., 2018; Testoni et al., 2021a; Lekes et al., 2022), foster a deeper appreciation for the value of life (Chan & Yau, 2010; Mak, 2013; Miller-Lewis et al., 2018; Tieman et al., 2018; Testoni et al., 2021), and improve a person's ability to provide emotional support to the dying (Lekes et al., 2022)

Considering spatiality in death education, we can create inclusive spaces for all without discrimination of race, gender, age, ability, and culture, be responsive to emotional needs, and promote a holistic understanding of and engagement with death and dying topics. It matters that we talk about death and dying. However, it also matters where we talk about death and dying, supporting a readiness towards talking about death and dying and engaging these discussions in places deemed safe and comfortable for the sharing and receiving of sensitive information.

8.4 Summary

Drawing on the concept of spatiality helps us further understand the ‘how, where, and when’ of death and dying conversations. The nature and availability of Space (both physical and emotional) have been highlighted as essential for promoting open communication, destigmatising conversations about death and dying, and creating supportive environments for addressing end-of-life matters constructively and compassionately. Consequently, affording spatiality for death conversations involves considering space beyond physical dimensions. It encompasses the idea of space in time, where conversations about death unfold within the context of past experiences, present moments, and future anticipations.

8.5 Temporality

Temporality (lived time) involves the subjective understanding of time, including the past, present, and future. The way a person feels can influence how they experience time and moments. Conversely, time's constraints, demands, and freedoms influence how a person feels, makes sense of, and deals with time in their lived experiences (Davidov & Russo-Netzer, 2022). This is reflected in research such as understanding the life world of mental health nurses (Wilson et al., 2023); understanding the lived experiences of nursing home staff (Gonella et al., 2022); the lived experiences of living with cystic fibrosis (Jessup & Parkinson, 2009); lived experiences of caregivers dealing with family with Parkinson’s disease (Bhasin & Bharadwaj, 2021); experiences of young women with breast cancer (Ahn & Lee, 2023); lived experiences of people over the age of 85 (van Rhyn et al., 2020); lifeworld perspectives of individuals living with dementia (Eriksen et al., 2022); exploration of existential anxiety (Davidov & Russo-Netzer, 2021); a theoretical paper discussing the use of researching lived experiences within the caring science (Palmér et al., 2023).

In this study, temporality in conversations about death and dying involves a complex interplay of the past, present and future. For example, reflecting on past conversations about death and dying could involve reminiscing about memories with the deceased and shared experiences, which influence how individuals approach conversations about death and dying.

While many of the themes have an affinity with the notion of temporality, Theme 2: shifting death and dying conversational perspectives – stakeholder group; Theme 2: perceptions about death and dying: Influences on death and dying conversations – individuals living with a life-shortening prognosis; and Theme 2: perceptions about death and dying: influences on death and dying conversations individuals without a life-shortening prognosis, illuminate the part temporality plays in conversations about death and dying.

8.5.1 Theme 2: shifting death and dying conversational perspectives – stakeholder group

The stakeholder group discussed conversations in the past, current conversations, and conversations about how they perceived how the pandemic affected these dialogues. The timing of the COVID-19 pandemic had a significant impact on participants and is important for understanding how they understood, conceptualised, and discussed death and dying. Prior to the pandemic, end-of-life decisions were made by the person who was ill and, where possible, their families and funerals took place as collective events. However, during the pandemic, healthcare professionals had to take a more significant lead in end-of-life care decisions (De Luca et al., 2023).

The challenges and emotional turmoil faced in not being able to see loved ones before their death amongst families were discussed by this group, highlighting the impact restrictions had on traditional mourning practices. Covid restrictions resulted in people being isolated, and there was an increase in mental health issues (Cao et al., 2020; Eisma et al., 2020). The significance of lack of physical presence and involvement in before and after death decision-making support and closure in the grieving process following the death of a loved one changed. The temporal aspect of navigating existential questions related to life and death and little control over the what and when in healthcare was disrupted; ordinary protocols could not be followed, and families often had little insight and communication around the ceasing of treatment and the introduction of comfort care (Robert et al., 2020). Comforting each other was delayed or at a distance; time was a barrier enforced by the restrictions with no time to be together or to say goodbye and reflect on that time (Hernández-Fernández & Meneses-Falcón, 2021).

The societal trend in managing death and end-of-life processes through the work of others, medical and business services (Hall, 2019; Borsatto et al., 2019) has meant that death and dying have become increasingly compartmentalised or separated from day-to-day care within healthcare institutions, COVID-19 brought death and dying into everyone's lives, not least through the media (Cinelli et al., 2020), and this meant people were talking more about their fears of death and dying valuing connectedness. The findings of the stakeholder group were mixed, with some suggesting people were now more involved in conversations about death and dying because of COVID-19 and others suggesting conversations about death and dying had not increased.

The contrasting reactions to death openness portrayed in the findings highlight the complexity of human responses to death and dying, ranging from acceptance and preparedness to denial and disbelief, reflecting the diverse ways individuals navigate the profound impact of mortality on their lives. Personal experiences, such as the loss of a loved one, a near-death experience, or witnessing the dying process, can shape a person’s perspective and understanding of death and dying (Haroen et al., 2023). To the same effect, identifying how they or the dying/deceased have lived a good life, whatever that means to each individual, can make thinking and talking about death and dying more reachable. Pehlivanova et al. (2023) investigated near-death experiences (NDE) and how they impacted the fear of death. Those who had NDEs had a significantly reduced fear of death than the control group. Participants in this study who had borne witness to death and dying could reflect on ‘good deaths’ and live with less death avoidance.

Over time, planning and approaching end-of-life matters with clarity and purpose highlights the temporal aspect of preparing for death and dying. Positive engagement in death and dying conversations can help people find a place of peace. Being together with significant others to share thoughts prior to and during the death and dying process matters.

8.5.2 Theme 2: perceptions about death and dying: influences on death and dying conversations – individuals living with a life-shortening prognosis

Some of the participants in this study shared that they did not attend funerals when they were children and were excluded from important family events. This exclusion may have resulted in feelings of confusion and lack of closure. One of the participants allowed their child to attend a family member's funeral as they felt that death was part of life and it was a way to demystify death. Fristad et al. (2001) suggest most children who attend funerals find it helpful to deal with death, especially if involved in the organisation. Funerals and their relevance to death and dying experiences are discussed in 8.4.3

As discussed in Chapter 1, section 1.4.2, there was a significant shift in the 20th century in how death is perceived (Parks & Prigerson, 2009; Howarth, 2007). Personal beliefs, attitudes and emotions can influence how people approach and cope with death, including attitudes towards end-of-life planning, grief and mourning. Individual, societal and cultural constructs are entwined, and all play a crucial role in how individuals understand and cope with death and dying and support and grieve for their loved ones. Participants discussed how their diagnoses affected their views on death and dying. In addition, they discussed their childhood experiences and the impact of their perspectives on death and dying, a temporal dimension of gaining insights and self-discovery in the face of mortality over time.

Many participants perceived religion/spirituality as essential for providing comfort and hope. Religious traditions can often provide a structured understanding of time, death and dying and the continuation of existence after death, offering individuals a framework for making sense of their limited time on earth and preparing for the transition to the afterlife (Ando et al., 2010; Harding et al., 2005; Piotrowski et al., 2020). Having a belief in an eternal soul, a divine plan, or a higher purpose can influence how the individual will perceive their impending death, their approach to end-of-life conversations, and find meaning and comfort in the face of mortality (Jackson et al., 2017; Harding et al., 2005; Piotrowski et al., 2020). Many of the participants discussed religion/spirituality and how it impacted their lives. For some, it was a source of comfort in that there was another life to go to following death.

Religion/spirituality can offer continuity, transcendence and hope beyond earthly existence's finite boundaries. The concepts of eternal life, reincarnation, or spiritual transformation can provide individuals with a broader perspective on time, death and dying and the cyclical nature of existence (Kokosalakis, 2020). This can offer solace, reassurance, and a sense of purpose as people deal with their journey towards death. Beliefs can shape how we perceive time, orientations toward the future and attitudes towards death and dying conversations. Individuals who live with a life-shortening prognosis may draw on past experiences, memories and spiritual practices to deal with their understanding of death and dying and engage in related conversations. Rego et al. (2020) explored the influence of spirituality on healthcare decisions, finding a connection between spiritual well-being, enhanced physical, emotional and functional wellness, and improved quality of life. Increased spiritual wellness was linked to reduced decision-making challenges, decreased uncertainty and a sense of being well-informed and supported. The findings in this study support this, as participants revealed spiritual wellness emanating from conversations about death and dying.

Tailored care that prioritises patient involvement in decision-making and addresses their spiritual requirements in death and dying conversations is vital for enhancing patient empowerment, autonomy, and dignity. Participants suggested reflecting on personal histories, illness ‘journeys’ and encounters with death and dying could inform good death perceptions, shape their attitudes towards dying and influence how they would/could communicate their beliefs, values and wishes. Religion and spiritual beliefs represent a dynamic interplay of past, present and future in shaping how a person responds to death and dying. Individuals can integrate past experiences and future hopes into their present understandings and find solace and connection in the face of their ultimate transition.

As social dynamics change, contemporary society may approach or interpret moral principles differently from previous generations. By appreciating the intricacies of change and loss, spirituality and its temporal domains can influence individuals to better engage in reflection, adaptation, and emotional processing surrounding death and dying topics. Taking time to engage in this reflective activity can lead to a deeper level of hope for oneself and those close to us. The temporal aspect of personal growth, resilience, and the evolution of relationships in the context of change and loss could act as a mechanism of change in how death and dying conversations are positioned within society.

8.5.3 Theme 2: Perceptions about death and dying: influences on death and dying conversations - individuals without a life-shortening prognosis

Participants talked about the fear and anxiety of talking about death. Similar to other studies, awareness of the limited time and uncertainty of what lies ahead and beyond death can lead to distress, avoidance and emotional turmoil (Mohammadpour et al., 2018; Çiftci et al., 2024). This uncertainty can hinder a person’s ability to engage in open conversations about death and dying. For some, conversations about death and dying may bring to light any unresolved issues, unmet goals, or unspoken feelings. The recognition of missed opportunities can strain relationships, create emotional distress, and hinder an individual’s ability to find closure and peace (National Cancer Institute, 2024; Woźniak & Iżycki, 2014; Macmillan Cancer Support, 2024; 2024a). In addition, facing one’s mortality and discussing death and dying can lead to feelings of isolation, loneliness and alienation (Abedini et al., 2020; Hajek & König, 2021). Impending death may create a sense of separateness from others, making it challenging to connect, communicate and seek support. However, for some participants, discussions about death and dying can be an opportunity to reflect on their lives, values and relationships. By considering their legacy and impact on others, they could find meaning and purpose in their mortality, leading to a sense of fulfilment and closure (Boles & Jones, 2021). Discussing death and dying allows individuals to plan for the future, make end-of-life decisions and ensure that their wishes are known. This proactive approach can provide a sense of control and empowerment, which could reduce anxiety and uncertainty around death.

Participants in this study discussed funerals and seemed more comfortable talking about this topic over others, emphasising the emotional importance of ritual and shared grieving. Funerals serve as a significant temporal marker that allows the individual to deal with their grief, honour the deceased, and find some form of meaning in the face of the loss. Funerals signify the transition from life to death and provide a structural framework for the individual to acknowledge the passage of time and the finality of death (Mitima-Verloop et al., 2019). By participating in funeral rituals, individuals can mark the end of life, reflect on their mortality, and engage tangibly with temporal dimensions of existence with others. As people gather at a funeral, they can share memories, mourn and celebrate the deceased's life, finding comfort in the shared experience of loss that transcends individual moments (Hoy, 2021). Funerals can allow the individual to engage with the cyclical nature of life and the interconnectedness of the past, present and future in ways that shape our understanding of time and death (Hoy, 2021). As individuals confront their mortality, reflect on the impermanence of life, and consider the temporal dimensions of existence, meaning, connection and acceptance can be fostered.

In contrast, a living funeral is an event held for the individual who is still alive to celebrate their life (Co-op, 2024; The Guardian, 2024). This is an opportunity to share memories, express gratitude, and connect with loved ones before death. Living funeral offers a unique temporal perspective on how individuals engage with their mortality, time, and relationships in the present moment. Celebrating a person's life while they are still alive allows for engagement with their past experiences, present circumstances and future hopes. This can foster a sense of mindfulness, gratitude, and presence in the face of death and dying. As discussed in Chapter 1, section 1.8.2. meaning management theory (MMT) suggests that individuals interpret events in their daily lives, allowing these interpretations to cultivate a richer and more purposeful existence (Tomer & Wong, 2011). Individuals can reflect on their legacy, values and impact on others in a tangible way. By inviting loved ones to share memories, express sentiments, and celebrate their life together, individuals can shape their narrative, convey their wishes and leave a lasting imprint on those they care about. Temporality is created by having a sense of continuity and connection across time. As seen in MMT, one of the tenets is meaning-making, where individuals actively interpret, construct, and generate significance for their experiences or circumstances. This process may involve social construction, narrative creation, pursuit of objectives, and self-improvement (Wong, 2008). Living funerals can provide individuals with a sense of closure, connection, and peace as they approach the end-of-life. By gathering loved ones, sharing stories, and expressing gratitude, individuals can strengthen relationships, resolve conflicts, and find comfort in acknowledging their life and impending death, fostering a sense of acceptance, closure, and connection in the face of mortality.

One final aspect that participants considered in this study was that of preparedness. Being prepared involves being future-oriented and acknowledging life's finite nature and death's inevitability. As mirrored in other studies, individuals can engage in advance care planning, make end-of-life decisions and communicate their wishes to ensure their preferences are honoured and affairs are in order (Thomas & Russell, 2023). However, Morrison et al. (2021) stated that for ACPs to be successful, they need to follow several steps that may be difficult to achieve fully. It is suggested that clinical practice settings can struggle to implement all steps because decisions are complex, uncertain, emotionally charged, and dynamic, influenced by various factors like age, health status, cultural beliefs, family input, clinician guidance, financial constraints, and caregiver burden. Patient preferences evolve and are not static. Proxies also face challenges translating past hypothetical discussions into present treatment decisions, navigating emotions and preferences, and advocating for patients' wishes. Prior directives may be lacking, poorly documented, overly prescriptive, or vague, hindering informed decision-making aligned with patient goals. External factors such as financial constraints, societal support systems, and institutional practices also shape treatment choices in real-world clinical scenarios.

Temporality was alluded to in other themes, themes 1 (Death conversation culture: the nature of death and dying conversations) and 3 (Readiness to engage in death and dying conversations) from the individuals living with a life-shortening prognosis group. Participants outlined how past conversations impacted current attitudes towards their mortality and changes experienced in themselves and their relationships with others following the diagnosis/prognosis. Individuals without a life-shortening prognosis, theme 1 (the nature of death and dying conversations) discussed wanting their future wishes and preferences to be clear. In addition, participants offered insights as to how their perspective on their mortality changed over time because it was perceived that in childhood, death is not considered and, in many instances, not talked about. In theme 3 (readiness to engage in death and dying), the change participants experienced through life and the different ways their families dealt with death and dying – leading to intergenerational norms, attitudes and behaviours were highlighted.

8.6 Summary

Death and dying conversations are about facing imminent loss, dealing with the practicalities of end-of-life care, and expressing emotions of grief and sadness. Being present in the moment allows for authentic and compassionate discussion about death and dying. Contemplating one’s future can include drawing on death and dying beliefs, spirituality and thoughts about the afterlife and considering legacy, memories and how life continues for those left behind. In the context of conversations about death and dying, temporality extends beyond just the passage of time. It is a multifaceted understanding of life and mortality's past, present, and future dimensions impacted by culture – the family, the environments we inhabit, the work we do and the experiences we have had. By embracing the temporal dimensions of conversations about death and dying, individuals can engage in meaningful reflections, express emotions authentically, and navigate the complexities of grief and loss with a deeper sense of connection to the past, present, and future. Understanding temporality in the context of death and dying can foster resilience, acceptance, and a sense of continuity in the face of life's inevitable transitions.

8.7 Corporeality

Corporeality (lived body) is the physical body or bodily presence in everyday life. It includes all that is felt, revealed, concealed, and shared through the lived body. We are all always present in the world, and as such, it is through our lived bodies that we communicate, feel, interact and experience the world (Davidov & Russo-Netzer, 2022). This is reflected in research within healthcare, as emotions are heightened because of illness, death and new life are seen in everyday practices (Whiley et al., 2022; Mastracci & Mourtgos, 2021; Fernandez, 2020; Mckiernan, 2018; Degerman, 2024; Slatman et al., 2016; Slatman, 2014). In this study, corporeality involves the sensory experiences associated with mortality, such as touch, sight, sound, and smell. These cues can create deep emotional responses and shape the conversation, influencing how a person perceives and processes experiences of death and grief. Other corporeal factors include nonverbal communication cues such as facial expressions, body language and gestures, and the physical state of the dying person, which can include symptoms and signs of illness or decline. Acknowledging the corporeal reality of the body can prompt discussions about mortality.

Two themes that particularly resonate with corporeality are Theme 1: We are all part of the sea from the stakeholder group and Theme 1: The nature of death and dying conversations from the individuals without a life-shortening prognosis group.

8.7.1 Theme 1: we are all part of the sea - stakeholder group

Emotional responses are a natural part of the human experience when reflecting on accepting vulnerability, a need for self-care, and emotional authenticity. The willingness to express and navigate emotions with honesty and self-compassion allows for a transformative approach to coping with adversity and nurturing emotional well-being. Several participants emphasised the embodied experiences, emotional responses, and self-care practices contributing to emotional well-being and coping with adversity allied to death and dying conversations. However, many of the participant's perspectives suggested that the public, in general, was not able to deal with the emotions evoked by conversions about death and dying.

As discussed in Chapter 1, section 1.8.1, terror management theory (TMT) posits that individuals tend to respond to the fear triggered by subtle cues of mortality (mortality salience, MS) through defensive, subconscious mechanisms. These responses are evident in a heightened disposition towards commonly accepted cultural beliefs in efforts to enhance self-esteem, which are often associated with societal standards and values. It has been theorised that subconscious mechanisms act as protective measures to reduce existential distress stemming from the awareness of mortality (Greenberg et al., 1986; Pyszczynski et al., 2015). This is reflected in the findings where participants perceived that society does not talk about death and dying as it is an emotive topic, and people as a defensive as they do not want confront their emotions.

Conversations about death and dying are inherently complex and multifaceted, encompassing a wide range of emotional, social, cultural, and existential aspects. Spiritual transcendence acts as a buffer against thoughts of death (Piotrowski et al. (2020), supporting TMT and the embodied nature and the diverse dimensions that shape the complexities of death and dying conversations. Often, death and dying conversations involve intense emotions such as fear, grief, sadness, and uncertainty. These conversations can elicit feelings, including vulnerability, empathy, compassion, and acceptance (Ando et al., 2010; Harding et al., 2005;). Many of these discussions can lead to introspection, spiritual exploration and reflection on our values and beliefs (Jackson et al., 2017; Harding et al., 2005; Piotrowski et al., 2020). However, there are challenges to having conversations about death and dying and feelings of discomfort, avoidance, or even misunderstanding can occur. Individuals may find it challenging to find the right words to express their emotions (Olsson et al., 2021).

In this study, many participants across all groups highlighted that terminology in death and dying conversations is multifaceted. There needs to be clarity, cultural sensitivity, emotional well-being, and legal and medical considerations that embody the implications of using specific terms in the conversations. Using appropriate terminology can help ensure all parties involved clearly understand the situation. Bartlet et al. (2022). found healthcare professionals referred to death in medical jargon, and families often used colloquial euphemisms.

Health professionals have acknowledged the importance of using patient-friendly and explicit language. Olsson et al.'s (2021) scoping review of end-of-life communication found terminology does not follow the guidelines on end-of-life communication in acute care settings in Australia, Canada, France, India, Ireland, Singapore, Sweden, UK and US. In medical and legal contexts, the terminology of end-of-life care terms are important because withdrawal of care versus palliative have different meanings and perceptions among patients, families and healthcare professionals. Misinterpretation in language can lead to misunderstands and conflicts, highlighting the need for clear and standardised terminology (Pieterse et al., 2012). Technical jargon, such as referring to cancer as spots or seedlings instead of metastases, can cause patient confusion. In addition, different cultural beliefs and attitudes towards death and dying are attached different meanings to the terms used. Thoughtful language within conversations about death and dying can provide comfort and support, making a difficult situation more bearable.

Death and dying is fundamentally emotional; conversations and reflections around the experience of death, dying, and grief elicit sensory and emotive visual representations and can return us to feelings of grief, some of which may have been historically manifested in a sense of physical pain (O'Connor, 2019; Dawson et al., 2021). In this study, different water analogies were used and shared relating to the concept of death and dying. Analogies of 'braving the waves', 'letting the water cover our feet' or 'being a test tube in a river' conveyed a profound perspective on isolation, interconnectedness and continuity in life and death. These analogies engage with thoughts of the movement of water - 'Being' toward death is contained within the flow of existence. Participants talked of life as a bucket of water or a test tube taken from the sea. The test tube/bucket separates the contained water from the larger expanse of water. However, there is the realisation that the water inside the test tube/bucket is the same as the river, emphasising our inherent connection to the whole – we are life and death, and we can transition in our openness to living with both realities. The analogy of reaching the sea suggests a transition or transformation, where the physical form (the test tube/bucket) dissolves, but the essence (the water) remains part of the vast expanse of the sea. This perspective reflects a sense of unity with the universe and a belief in the enduring nature of the self beyond physical boundaries, offering a unique and contemplative view of life, death, and the continuity of 'Being'. This analogy with water can provide a sense of peace, an understanding that even when considering mortality, we can still be connected and part of the landscape of life and living. Analogies are flexible tools that have been used in teaching but can be used in any field (Gray & Holyoak, 2021).

In using analogies to try and understand the interplay of experience and its emotionality and connectedness or corporeality, as well as how we think and feel toward death and dying conversations, we draw our attention to the role of hope. Hope sustains individuals through challenges, inspiring resilience and fostering a sense of connection to a greater purpose or possibility (Murphy, 2023). The acknowledgement of hope as a powerful and concrete force highlights its capacity to instil courage, motivation, and a sense of optimism in the face of uncertainty or adversity. Again, this can be embodied and impact how we behave around and in response to death and dying conversations.

8.7.2 Theme 1: the nature of death and dying conversations - individuals without a life-shortening prognosis

The avoidance of discussing death and dying is a complex relational embodiment of experiences, physical discomfort, and societal taboos (Baker et al., 2016). Participants revealed the physical sensations, bodily responses, and visceral reactions that shaped their discussion regarding mortality.

The avoidance of death and dying conversations from a corporeality perspective may stem from the discomfort with the physical aspects of mortality, for example, the sight of a dead body, the ending of bodily function and the sensory experiences associated with dying. Mowll et al. (2015) researched the experience of viewing or not viewing the dead body and found that for some, viewing provided meaning, and for others, there were regrets and intrusive images. Confronting the reality of death can evoke feelings of vulnerability, fear and existential unease. As mirrored by the participants in this study, some could challenge these feelings and address death openly and candidly, similar to the worldwide success of Death Cafes (Death Cafes, 2024).

The avoidance of death and dying conversations can be influenced by societal norms, cultural taboos and the stigmatisation of death in contemporary Western society (Kellehear, 2007). Participants suggested society as a whole has a fear of death and dying. The corporeal indicators, such as the physical signs of ageing and illness, can often be marginalised, hidden or even sanitised in mainstream conversations (Fang, 2024). Participants shared how they were protected in their childhood from the emotions of death and dying. TMT suggests that the elderly are a reminder of death for young people and that the death anxiety of young people who are in close contact with the elderly increases, and self-esteem and interpersonal communication deteriorates (Rababa et al., 2021). Participants suggested that death conversations are taboo. The medicalisation of dying within our society could further perpetuate the avoidance of conversations about death and dying.

Integrating embodied experiences, physical sensations, and somatic responses regarding death and dying could offer a path to reducing discomfort and reluctance to engage with the topic. If we could acknowledge these corporeal aspects, we could develop a more grounded, authentic, and embodied relationship with death. This would allow us to confront our bodily vulnerabilities, fears, and existential uncertainties in a more holistic manner.

Participants revealed the need to normalise death and dying conversations. Normalising these conversations entails recognising that death is a natural part of life (Wilson et al., 2023). Integrating discussions into everyday interactions and experiences can help to demystify the topic. Participants mirrored this by revealing their conversations with family when they were younger. By grounding conversations about death in the corporeal aspects of existence, individuals could confront the physicality of death and dying and the impermanence of life in a more tangible and embodied manner.

Corporeality was alluded to in other themes. In theme 2 of the individuals without a life-shortening prognosis group (Perceptions about death and dying: influences on death and dying conversations), there were discussions of the emotions felt when witnessing death and the emotions, both positive and negative, of attending funerals. There were also discussions of the anxiety felt about the subject of mortality.

Awareness of bodily sensations and physical vulnerabilities can prompt individuals to face their fears more directly and openly. Price and Hooven (2018) suggest that mindful attention to inner body awareness helps individuals reconnect with their deep bodily states, enabling them to modify maladaptive stress reactions and ingrained patterns. This is done by using Mindful Awareness in Body-Oriented Therapy (MABT), which combines mindfulness and hands-on guidance with teaching individuals to notice the subtle physiological sensations, which improve emotional regulation. Acknowledging the corporeal aspects of death, fragility, and physical decline may help individuals cultivate a deeper appreciation for the transient nature of life and the interconnectedness of physical existence.

8.8 Summary

Corporeality, as shared through the lived body and acknowledging a range of emotions in the context of death and dying, is an integral component of human conditions and is valuable. Fear, grief, acceptance and hope are all intricate aspects that individuals may have to deal with when faced with death and dying. By acknowledging these emotions, healthcare professionals and support systems can offer compassionate care that addresses the holistic needs of individuals facing mortality issues. This could encourage a shift towards destigmatising emotional expression and promoting open conversations about death by fostering a culture of acceptance, empathy, and authenticity in which individuals feel empowered to share their emotions and experiences without fear of judgment or rejection. Navigating death and dying openness with the self and others can be experienced through the lived body of health and illness, the viewpoint of the patient, carer or bereaved.

Being at ease with death and dying can be challenging as we wrangle with our multiple identities of parent, child, professional, and friend and ‘Being’ within a society that, to some extent, still dictates the how, the when and the who leading on from the medicalisation and professionalisation of death. Being toward death is internalised – we feel the fear, the emotion of loss, and anticipatory grief for self and others. The motivation to be open comes from within the self. However, it is scaffolded by our experiences, how things have gone before, the bodily comfort of the self and with others, and the proximity toward the death of self or others can be felt within.

8.9 Relationality

Relationality (lived human experience) involves social, emotional, and interpersonal connections individuals form with others. Relationships influence people’s experiences, sense of self, and how we communicate, share, and create an experience with others (Davidov & Russo-Netzer, 2022). Relationality is reflected in research within many health-related topics (Kurz et al., 2022; Vidovićová & Menšíková, 2023). In relation to this study, relationality encompasses the complexity of interpersonal connections within conversations about death and dying. It highlights the importance of relationships between the dying person, their families, caregivers, and healthcare providers. Relationality also considers the influence of cultural beliefs and societal norms on how death and dying are perceived, discussed, and experienced. These factors shape how a person engages with and supports another during death and dying conversations. As mentioned in 8.3, 8.4 and 8.5, there are links from many of the themes to the four lifeworld existentials. However, three themes resonated with relationality: Theme 3: holding hands with death and dying – stakeholder group; Theme 3: readiness to engage in death and dying conversations – individuals living with a life-shortening prognosis; and Theme 3: readiness to engage in death and dying conversations – individuals without a life-shortening prognosis.

8.9.1 Theme 3: holding hands with death and dying - stakeholder group

Participants shared experiences that shaped their understanding of death. However, the contrasting reactions to death openness portrayed in the findings highlight the complexity of human responses to death and dying, ranging from acceptance and preparedness to denial and disbelief.

Findings revealed that discussing positive generativity and legacies can support contentment towards the end of life and bereavement. The loss of a significant other often illuminated the profound impact of death, prompting reflections on the importance of communication, understanding, and connection with loved ones before it is too late. The transformative nature of loss in awakening a deeper appreciation for the value of relationships, the power of shared experiences, and the significance of expressing sentiments and thoughts to those we care about while they are still present have been reported in the literature (Jolly et al., 2019). Relationality, if harnessed and shared, could help people engage in generativity and legacy so that their life exists beyond death. In addition, the bereaved can, through stories shared, understand the meaning and purpose in their loved one's lives, and this is realised and celebrated before death occurs. Research suggests the importance of relationships, communication, understanding, and connection with loved ones, highlighting the transformative nature of loss in fostering a deeper appreciation for shared experiences and the significance of expressing sentiments before it is too late (Generous & Kelley, 2020). Relationality accentuates the relational aspects of engaging in generativity, creating legacies, and celebrating the meaning and purpose of life through shared stories and connections with others, as seen in the themes discussed previously.

Many participants highlighted the role of community in conveying messages about death and dying is essential for fostering understanding, support, and shared meaning. Communities can be a platform for sharing narratives, experiences, and cultural beliefs about death and dying (Hansford et al., 2023). Through these communal discussions and rituals, individuals can make sense of death and dying by drawing on shared values, traditions, and perspectives. Communal engagement allows for transmitting knowledge, wisdom, and emotional support, creating a sense of solidarity and interconnectedness in facing the universal experience. Moreover, community involvement in conversations about death and dying helps to break down barriers, reduce stigma, and promote open communication about end-of-life issues.

Community and wide society, through both spatiality and relationality, can foster spaces and relationships that support dialogue, reflection, and mutual support, empowering individuals to express their thoughts, feelings, and concerns about death and dying in a safe and accepting environment. As mirrored in the findings, a collaborative approach to discussing death encourages empathy, compassion, and understanding among community members. This can foster a culture of inclusivity and support for those navigating the complexities of mortality (Aoun, 2022).

There are challenges to the traditional roles and expectations surrounding caregiving, intergenerational support and familial responsibilities (Antonucci et al., 2007). The conventional expectation that children will oversee the care of their parents as they age is being reshaped by the reality of extended lifespans and changing social structures. This is reflected in a review by Luichies et al. (2019) regarding the caregiving experience of adult children. Results showed that the challenges faced by children who care for their elderly parents involve navigating conflicting norms and values.

Parents' longevity can disrupt traditional patterns of intergenerational support and caregiving (Lestari et al., 2023; Bui et al., 2022) as families grapple with the complexities of providing care for ageing parents while also attending to their needs, relationships, and well-being, as supported by the findings of this study where participants revealed their care of ageing parents. The prolonged lifespan of parents can lead to a shift in power dynamics, decision-making processes, and emotional dynamics within the family as adult children navigate the complexities of negotiating care, autonomy, and mutual respect in the context of ageing and longevity (Carr & Utz, 2020). These changes in family dynamics highlight the need for open communication, flexibility, and empathy in addressing caregiving's evolving needs and challenges across generations.

Findings also suggest that the stakeholder participants saw their role as a privilege. Career choices were driven by a need to help people, illuminating the transformative power of empathy, compassion, and service in shaping individual identities, professional trajectories, and societal contributions (see also Bailey et al., 2018; Laaser & Karlsson,2021). Participants embraced their innate desire to make a difference; they embodied a commitment to social responsibility, ethical practice, and human connection that enriched their lives, fostered a sense of purpose, and created a ripple effect of positive change regarding conversations about death and dying.

Viewing the role as a privilege also invites a reflective exploration of the deeper meanings, motivations, and aspirations that underlie one's professional identity and purpose. By embracing the privilege of work, individuals can cultivate a sense of agency, creativity, and resilience that empowers them to navigate challenges, seize opportunities, and contribute to positive change in their organisations and communities regarding death and dying.

However, the dichotomy of work and home was also highlighted, and discussions suggested challenges in maintaining boundaries, managing stress and fostering a sense of balance and well-being across work and daily life, as seen during the global pandemic. Chung et al. (2022) investigated the experiences of parenting and working from home. Their results showed a poorer work/family life balance linked to higher parenting stress and increased marital conflicts. However, there is the potential for transcendence where aspects of work and home life, such as values, skills and insights, can intersect and influence each other meaningfully. This is reflected in the meaning management theory (as discussed in Chapter 1, section 1.8.2). MMT posits that the inclusion of values and beliefs can protect against the fear of death and allow for death acceptance (Wong, 2008). By integrating various aspects of work and home life, the individual may discover personal growth and a deeper sense of fulfilment, fostering a more authentic, balanced way of living. The dichotomy of work and home life allows for exploration and growth. Individuals can transcend boundaries, cultivate connections, and forge a more holistic and meaningful existence.

This discrepancy between family members' understanding of the participants' job roles can reveal underlying tensions, misperceptions, and value conflicts that shape familial relationships and individual identities. The lack of understanding may stem from differences in generational attitudes (Alferjany & Alias, 2020), cultural beliefs (Maddux et al., 2021; Arieli et al., 2019), or personal experiences that shape perceptions of work and success. The divergence in values, priorities or aspirations between the participants in this study and their families can contribute to a sense of judgement or criticism that hinders open communication and mutual support in navigating the complexities of professional life with the family.

By engaging in reflective dialogue, acknowledging differences, and embracing diverse perspectives, participants and their families could deepen their connections, foster mutual understanding, and cultivate a supportive environment honouring individual autonomy, professional growth, and personal fulfilment within the context of family life. Haim-Litevsky et al. (2023) aimed to understand the connection between well-being, sense of belonging, and connectedness in healthy adults' daily activities. Findings suggested a connection between engaging in significant activities and feeling a sense of belonging, connectedness, and well-being.

8.9.2 Theme 3: readiness to engage in death and dying conversations - individuals living with a life-shortening prognosis

The findings had a focus on interpersonal relationships, emotional dynamics, and changing roles within the family unit to cope with life-shortening illnesses, highlighting the importance of understanding and navigating relational aspects during challenging times. Recognising the positive contributions made by others highlights the reciprocal nature of human interactions and the profound impact of shared experiences in fostering empathy, gratitude, and a deeper appreciation for the interconnectedness of lives. Reflecting on the influences of individuals from our past, expressing thankfulness for the connections and memories that have enriched our lives, and fostering a sense of interconnectedness, empathy, and appreciation of human relationships can profoundly impact personal growth and well-being (Garland et al., 2015; Zhang et al., 2021).

The challenge of discussing death and dying with immediate family members reveals the intricate dynamics of familial relationships, emotional vulnerability, and existential confrontations within the intimate sphere of personal life. There is an emphasis on the relational aspects of navigating conversations about death and dying within the family, highlighting the complexities of familial relationships, emotional vulnerability, and existential confrontations that shape interactions within the personal and intimate space of family life (Horning & Bowen, 2023).

When faced with the prospect of talking about death and dying with immediate family, individuals can encounter heightened emotions, complex histories, and deeply ingrained patterns of communication that can complicate these conversations (Thomas et al., 2017). Participants mirrored this as they discussed their difficulties with their families. The closeness and intimacy shared with family members can amplify feelings of vulnerability, fear, and discomfort as the emotional stakes are more profound within the family unit. For example, in relation to caring for a person with a life-limiting illness, research has suggested family caregivers experience emotional stress and decision-making challenges linked to uncertainty and remorse for an extended period, potentially resulting in depression and intensified feelings of grief over months or even years (Laidsaar-Powell et al., 2013 & Waldrop & McGinley, 2022; Martin et al., 2016). However, ethical dilemmas such as withholding/withdrawing treatment, nutrition/hydration issues, resuscitation orders, palliative sedation and authentic communications can add to this remorse (Ong et al., 2012; Garrido & Prigerson, 2013; McCabe & Coyle, 2014).

Discussing death and dying with immediate family members can evoke a range of responses, from denial and avoidance to deep-seated anxieties and unresolved conflicts that may surface when confronting the fragility of life and the inevitability of death. The familial context can magnify the intensity of these emotions, creating a charged atmosphere where individuals may struggle to find the right words, emotions, and gestures to express their thoughts and feelings about mortality. Hamano et al. (2017) explored conflict among families of people who had died in palliative care units. Findings revealed many families experienced discord during the end-of-life care stage. Some family members would seek dominance in the decision-making and communications, indicating the likelihood of family conflicts arising.

The familial bond itself can act as both a barrier and a bridge to discussing death and dying. On the one hand, the deep emotional connections and shared histories within families can create a sense of solidarity, support, and understanding that facilitates open communication and mutual comfort in facing death together. Alternatively, familial dynamics, past traumas, and unspoken expectations can hinder honest and meaningful conversations about death, leading to misunderstandings, conflicts, and silences that impede the sharing of thoughts and emotions surrounding mortality. By embracing the challenges and opportunities that arise in discussing death with immediate family, individuals can deepen their connections, foster resilience, and cultivate shared understandings.

8.9.3 Theme 3: readiness to engage in death and dying conversations - individuals without a life-shortening prognosis

Exploring the readiness of individuals without a life-shortening prognosis to engage in conversations about death and dying revealed complex dynamics that intertwine personal beliefs, societal norms and relational influences. The findings revealed that trust, empathy and mutual understanding within relationships can create a safe space for individuals to share their hopes, fears and beliefs about death and dying. Relationality was alluded to in Theme 1 from the individuals living with a life-shortening prognosis (Death conversation culture: the nature of death and dying conversations). Participants talked of conversations about death and dying with various family members and how these people had an impact on their lives.

Storytelling can serve as a powerful medium for individuals to explore thoughts, emotions, and beliefs in a relational and interconnected way (Lugmayr et al., 2017; Rutledge, 2006). Shared stories foster mutual understanding, empathy, and connection, providing a sense of community. By sharing stories, individuals can process complex emotions and articulate their values and beliefs to others. Participants shared stories, providing a sense of comfort and community. The global movement promoting death positivity and death awareness to enhance dignity, compassion, and social support in death and dying supports fostering conversations and acceptance of death and grief. Gatherings allow the sharing of stories and loss experiences (Incorvaia, 2022; Miles & Corr, 2017).

An initiative called the Reflection Room is an arts-based storytelling activity which was evaluated by Carter et al. (2023). Survey results revealed that there was emotional sharing and thoughtful contemplation. Individuals who visited the Reflection Room reported feeling more at ease discussing and thinking about mortality. Storytelling interventions positively affect the mental well-being of adults and children Gentle et al. (2020) and Gillam (2018). In this study, participants spoke of the stories they shared with neighbours, friends, and families, which provided support, connection and interconnectedness. Storytelling can empower families and individuals, release emotional stress, create meaning from their experience, and connect with others over shared stories (Akard et al., 2015; Bosticco & Thompson, 2005; Hanlon et al., 2019). Storytelling can be seen as a cultural resource that normalises experiences, enhances social bonds and reduces feelings of isolation

(Kellehear, 2014; Blake et al., 2020). Storytelling has been found to help children cope with grief by providing an outlet to express their emotions and using artwork to communicate those experiences Glazer and Marcum (2003).

Existential questions about the meaning of life, legacy and the continuity of existence beyond death shape a person's perspective on death and dying. Participants revealed the social influences that shaped their readiness to discuss death and dying and how interactions with family, friends and broader societal norms can either encourage or discourage such conversations. Cultural taboos, stigmas surrounding death, and the societal avoidance of end-of-life topics can contribute to a reluctance to broach death and dying subjects. Conversely, supportive social networks, open communication and culturally embedded rituals that honour death can create positive relationships for individuals to express their thoughts and feelings about death and dying.

Funerals and rituals were discussed from a spatial perspective but can also be situated within a relational perspective. Rituals can hold profound significance in fostering connection, support, and shared meaning-making (Hoy, 2021). Many participants felt this connection and support in this study when attending funerals. Funerals can serve as a relational event that brings individuals together to honour the deceased, support the grieving process, and strengthen social bonds within a community. Individuals engage in mutual support, empathy, and solidarity by participating in funeral rituals, creating a relational network of care and compassion that transcends individual grief and isolation (Hoy, 2021). Attending religious rituals can enhance well-being (Koenig et al., 2012; Chen et al., 2020), reduced risk of mortality (Chida et al., 2009; Gillum et al., 2008; Musick et al., 2004), depression (Barton et al., 2013; Barton et al., 2013a; Li et al., 2016), and suicidal thoughts (Rasic et al., 2011). Funerals can facilitate the transfer of collective memory and storytelling across generations. By engaging in funeral traditions and rituals passed down through families and communities, individuals connect with their cultural heritage, ancestors, and shared history of coping with death (Hoy,2021).

Religious rituals evolved to establish and nurture social connections within human groups (Clarke et al., 2013), with research suggesting behaviours embedded in religious rituals promote feelings of social cohesion, such as shared attention (Fredrickson & Branigan, 2005; Wolf et al., 2015; Fredrickson, 2013), common objectives (Reddish et al., 2013), communal music (Kreutz, 2014; Pearce et al., 2015; Pearce et al., 2016), social connection at mealtimes (Jaremka et al., 2017), social bonding with people who attended the funeral (Charles et al., 2020) and moderate alcohol consumption (Kirchner et al., 2006; Sayette et al., 2012). Religious rituals, through these behaviours, can facilitate social bonding effectively. In contrast, following the global pandemic, funerals and rituals were stopped. De Oliveira Cardoso et al. (2020) suggested that families were not able to fulfil their last homage to their loved ones, causing feelings of disbelief, isolation and the possibility of complicated grief in the future. Funerals, viewed through the lens of relationality, highlight the transformative power of communal rituals in navigating the complexities of death, grief, and remembrance within the context of interconnected human relationships.

Relationality was alluded to in another theme, Theme 1, from the individuals living with a life-shortening prognosis - Death conversation culture: the nature of death and dying conversation). Within this theme, participants shared conversations about death and dying with family members and how they had an impact on their lives. The conversations highlight the significance of relationships and communication within families when addressing death and dying. Their narratives highlighted how conversations shaped their understanding of death and deepened their connections with their loved ones during challenging times. Recognising the relational aspects of death and dying conversations can shed light on the importance of supportive relationships and effective communication.

8.10 Summary

Emotional bonds and attachments among individuals can play a crucial role in conversations about death and dying. Expressions of love, empathy, compassion, and understanding can strengthen relationships and provide comfort. Cultural sensitivity, respect for diversity, and awareness of social dynamics are needed to support people from different backgrounds when dealing with mortality.

Relationality highlights how our relationships with the self and others impact death and dying openness. Our level of comfort or ease with this subject matter is impacted by intergenerational attitudes and behaviours that we either internalise or are at least conscious of in our approach to others. How we communicate with family, friends, and peers about death and dying is a result of tradition, socialisation and, dominantly, our spiritual and religious belief systems. Interventions that draw on generativity and legacy leaving and promote memory sharing via storytelling can support conversations that lead to death and dying experiences, perceptions and wishes.

8.11 Implications and contributions to knowledge

The thesis explored the lived experiences of death and dying conversations amongst people with or without a life-shortening condition and key stakeholders of the death positivity movement. The findings offer valuable insights and contributions to understanding attitudes towards death and exploring different life experiences. Understanding the influences of an individual's openness and readiness to engage in conversation about death and dying, valuable insights into the intricacies between age, life experiences, spiritual belief systems, and perceived proximity to death on perceptions of death and dying and end-of-life decisions have been offered. Key messages are highlighted below, along with areas for future research.

8.11.1 Age and life experiences

Age and diverse life experiences shape an individual's perception of death and can enhance our understanding of generational differences in attitudes towards mortality. Younger individuals may approach discussions about death with curiosity and openness, while older adults may draw on their life experiences to navigate conversations with wisdom and acceptance. Further research is required to investigate how age and diverse life experiences influence an individual's perspective on death. Future research could shed light on generational differences in attitudes towards death and dying. Understanding how younger people's curiosity and older adults' wisdom from life experiences can impact death and dying conversations could inform policy decisions related to end-of-life care, advanced planning, bereavement, and education that can be tailored to different age groups.

8.11.2 Spiritual/Religious belief systems

Spiritual and religious belief systems impact attitudes towards death. This study found that people, irrespective of their health status or experiences of death and dying, hold on to some spiritual perceptions and values in the face of death and dying. Although belief systems exist for some individuals, others may possess an eclectic range of spiritual views on death and dying. An openness toward where these views are derived from and exploring them enables an openness of individual/relational coping in death and dying and related conversations, which is paramount to clinical, educational and death openness practices. We should not assume that religion/spirituality is irrelevant or that individuals with a specific religion will have a specific belief system. So, where possible, to bring death and dying conversations more into the public discourse, there should be an attempt to promote such with a spiritual openness. Future research could explore how religious and spiritual beliefs influence a person’s end-of-life decision-making, grief processes, and approaches to death and dying. Research could investigate how different faith traditions and spiritual practices shape an individual’s experiences and preferences surrounding death, including rituals, mourning practices and beliefs in the afterlife. Understanding these aspects has policy implications that could involve promoting cultural competence and sensitivity when dealing with death and dying to accommodate the diverse religious and spiritual beliefs that are found within Western society. Healthcare providers could receive training on how to respectfully address and support patients' often eclectic spiritual needs during the dying process and in conversations about death and dying. Policies could focus on ensuring that individuals have the freedom to practice their religious and spiritual traditions to foster a more inclusive and supportive environment.

8.11.3 Proximity to death

Acknowledging an individual’s proximity to death, whether through personal experiences, health conditions, or cultural contexts, influences their acceptance and fear of mortality is crucial. This study found a desire for generativity amongst adult populations with or without life-shortening conditions. In addition, an openness toward death and dying conversations because of the COVID-19 pandemic bringing death into everyone's homes and the restrictions and experiencing loss through that time emerged. However, this openness may be transient, but there does appear to be greater death awareness and increased value on cultural rituals and support for our relational bereavement journeys. Future research could capitalise on these findings and the readiness for death and dying conversations at different junctures, including wider society, communities and healthcare organisations and across illness trajectories. For example, developing and testing a tool to measure conversation readiness for death and dying. Robust tools could be integrated into standard care practices to ensure that conversations about death and dying are initiated at appropriate times and tailored to individual needs. By identifying readiness levels early on, healthcare professionals can better support patients' and their families' needs, fostering effective communication and person-centred care.

8.11.4 Holistic development and cultural beliefs

Individuals' holistic development, encompassing psychological, emotional, social, and cultural dimensions, is central to understanding how cultural beliefs and values impact attitudes towards death. Cultural norms, rituals, and practices surrounding death play a significant role in shaping individuals' approaches to discussing mortality and coping with loss. This study found that the language and terms used in death and dying conversations matter and should be attuned to those involved in discussions. Adult conversations about death and dying should be considered normative within and outside of clinical settings as they can contribute to holistic development across life trajectories and enhance relationships with peers and significant others. Furthermore, the interconnections between age, life experiences, spiritual beliefs, and cultural influences on individuals' attitudes towards death and openness in conversations are nuanced and informed narratives about death, foster acceptance and resilience in the face of mortality, and cultivate a more death-positive society that values dignity, empathy, and holistic well-being.

Future research could explore the efficacy of using media, workshops, music, and the arts, highlighted in Chapter 5, Theme 2) in clinical practice for adults and families and broader educational/social events in the community. Research could explore the effectiveness of integrating these diverse forms of interventions into community settings, healthcare practices and education to improve conversations about death and dying. Advocating for increased funding and resources to support community programs and promoting collaboration between healthcare providers, community organisations and policymakers to normalise conversations about death and dying is essential to ensuring death and dying conversations are widely accepted, and the death positivity movement is capitalised. Education, health and social care policies should emphasise the importance of public education and awareness campaigns to normalise conversations about death and dying.

8.11.5 Normalising death-related discussions

Strategies that could normalise death and dying conversations include:

1. Education and awareness programs education initiatives should be further implemented in schools, workplaces, and communities to increase awareness and knowledge about death and dying, Evaluate education and training offered for health care professionals, and explore whether they support practitioners to engage in death and dying conversations
2. Expand the Death Café movement for caregivers and volunteers with focused sessions on ways to engage in death conversations.
3. Create safe spaces for death and dying conversations (within and outside of clinical settings): Establish support groups, discussion forums, or workshops focused on death-related topics to provide a safe environment for the individual to share their thoughts and experiences. Encourage open dialogues within families and social circles to normalise conversations about death and reduce stigma.
4. Use media and arts: Use media platforms, literature, films, and art to portray diverse perspectives on death and dying, fostering conversations and reflection. Organise events such as film screenings, book clubs, or art exhibitions to engage the public in discussions about mortality.
5. Advanced care planning earlier in disease trajectories: Promote advanced care planning discussions to help individuals articulate their preferences for end-of-life care and communicate their wishes with loved ones before the end-of-life stage of illness trajectories (the last 12 months of life). Encourage the completion of advance directives, living wills, and healthcare proxies to

ensure individuals' end-of-life wishes are respected. These can be arranged many years in advance of any need.

6. Training in death and dying communication skills: To facilitate sensitive conversations about death and dying, all healthcare professionals (not just those working in end-of-life care settings), caregivers, and community members should receive training in effective communication skills. Workshops focused on active listening, empathy, and emotional support should also be provided to enhance dialogue during difficult discussions.
7. Cultural sensitivity and inclusivity: Recognise and respect diverse cultural beliefs, traditions, and practices related to death and dying. Ensure that discussions about mortality are inclusive and culturally sensitive, acknowledging the unique perspectives of different communities and making no assumptions based on documented religion.

Implementing these strategies could help individuals and communities better prepare for and normalise discussions about death, fostering a more open, supportive, and informed approach to this universal aspect of the human experience.

8.12 Limitations and strengths of the thesis

This study has several strengths and limitations. Interpretive phenomenology drawing on van Manen's lifeworld existentials is challenging for novice researchers to apply due to the philosophical nature of the approach. My interpretations influenced the findings, and my biases influenced data analysis. However, being reflexive, noting my decisions throughout the process, acknowledging any emotions and reactions to the data, and providing a narrative add trustworthiness to the findings. In addition, findings were discussed with my supervisors to reach some middle ground and achieve descriptions and interpretations that would be accessible to the readers and enable them to enter the participants' world and thus engage in understanding the lived experience of death and dying conversations.

The strength of the methodological approach selected allowed me to understand my perspectives and how they influenced the research process and data collection. The study took a more philosophical approach rather than a rigid methodology, demanding that I extract its core principles and incorporate them into my study, allowing for potential critiques regarding the application of philosophy in practice. I endeavoured to simplify the philosophical principles for clarity and examination to enhance transparency in my decision-making process. The lack of a predetermined methodological structure required extensive interpretation to maintain the credibility of my findings, consistently assessing whether my research design effectively revealed the phenomenon under study. While my study does not seek extensive generalisations, participants' viewpoints may hold relevance for individuals facing similar circumstances. I am aware that I may not have fully conveyed my perspective throughout this study, but endeavoured to push towards a fusion of horizons. The hermeneutic circle principles highlighted the importance of analysing data at a deep level over time and engaging continuously with it. The methodology used guided the depth of interpretation, moving beyond mere description but staying within the boundaries of the data and the hermeneutic circle.

The methods had several limitations. First, collecting data using focus groups has the potential for power differentials and dominant personalities to take over the group discussions. In addition, participants could be reluctant to share their stories in a group setting, which could limit the richness of the data (Nyumba et al., 2018; Sim & Waterfield, 2019). Focus groups online require specific equipment and technical ability and cannot guarantee a distraction-free or confidential environment. In addition, reading body language is more challenging to observe online (Saarijärvi & Bratt, 2021; Flayelle et al., 2022). Furthermore, it may be difficult to recruit participants who can represent the phenomena that are being researched (Nyumba et al., 2018; Sim & Waterfield, 2019). However, I found focus groups to be dynamic and interactive environments for exploring complex topics, generating rich data, and uncovering diverse perspectives that may not have emerged in individual interviews. In addition, there were no issues with geographical distances (Saarijärvi & Bratt, 2021; Flayelle et al., 2022). Focus group participants felt engaged and motivated to share their opinions, experiences, and stories in what could be seen as a supportive group setting (Braun & Clarke, 2013; Moser & Korstjens, 2018; Hennink et al., 2020).

The second limitation is that of the sample of participants living with a life-shortening condition. Most participants interviewed lived with Motor Neurone Disease, which may introduce bias to the study’s findings and not represent diverse perspectives and experiences of the diversity of life-limiting illnesses people live with. However, this study offered a unique insight into the participant’s experiences of dealing with conversations about death and dying and how there appears to be a resilience about them that cannot be explained, offering the possibility of future research specifically designed to understand the lived experiences of MND and how it has impacted a person perspective to life and death. There could be difficulty in comparing findings with other studies involving different populations or conditions, limiting the ability to draw broader conclusions. However, this study provided a focused insight into the unique aspects of living with a life-shortening prognosis and how it affects perspectives on the conversations had about death and dying.

A third limitation relates to the lack of cultural diversity of participants. High-context and low-context cultures are terms used to describe how cultures differ in their communication styles and reliance on contextual cues (Yang et al., 2020; Kim et al., 1998; Chen, 2023). In high-context cultures, communication relies heavily on implicit messages, nonverbal cues, and shared cultural understandings. These cultures place importance on relationships, group harmony, and indirect communication. Examples of high-context cultures include Asian, Middle Eastern, African, and Latin American cultures (Yang et al., 2020; Kim et al., 1998; Chen, 2023).

In low-context cultures, communication is more explicit and direct, and verbal messages convey meaning (Yang et al., 2020; Kim et al., 1998; Chen, 2023). These cultures emphasise individualism, clarity, and direct communication. Examples of low-context cultures include Western cultures, such as those in North America and Northern Europe (Yang et al., 2020; Kim et al., 1998; Chen, 2023).

Understanding the distinction between high-context and low-context cultures is essential in intercultural communication and research contexts. It helps recognise how communication styles, information sharing, and social interactions vary across cultural groups.

Van Manen’s (1998; 2016) lifeworld existential framework may not fully account for the diverse cultural perspectives on death and dying. As mentioned above and in Chapter 1, section 4, different cultures have unique beliefs, rituals and practices surrounding mortality that may not be adequately addressed in his existential analysis. The framework may not consider how aspects of race, ethnicity, gender or socioeconomic status shape individuals’ experiences of death and dying and influence how people perceive and engage with mortality. In addition, the framework may not explicitly address power dynamics that influence conversations about death and dying. Socio-political factors, such as access to health care, social inequalities, or institutional practices, can shape individuals’ experiences of mortality but might not have been fully integrated into the analysis. Van Manen’s work may overlook how structural injustices impact individuals' encounters with death. Issues like healthcare disparities, end-of-life care access, or systemic inequalities can affect how different groups experience and navigate death and dying.

For future research and cross-cultural studies on death and dying, researchers must navigate the differences in communication styles, cultural norms, and implicit meanings between high-context and low-context cultures. Interpreting findings may require sensitivity to cultural nuances, contextual understanding, and the ability to decode implicit messages embedded within participants’ responses. Researchers must engage in reflexivity and be culturally sensitive to navigate the impact of high and low-context cultures on research findings. Acknowledging cultural influences, adapting research approaches, and interpreting data within the appropriate cultural frameworks are essential to generating accurate, meaningful insights into how cultural contexts shape individuals’ perceptions and experiences of death and dying. Addressing the cultural and social-political gaps could enrich van Manen’s work by providing a more comprehensive understanding of how existential themes intersect with diverse cultural perspectives and societal contexts of conversations about death and dying.

The final limitation and strength is that I am a novice researcher. I believe my interest in death and dying and the phenomenological methodology and methods used offset this. I engaged in wide reading that helped me to better theoretically and empirically appreciate the topic under study and the research approach. In addition, my experience of caring for individuals, where I discussed death and dying regularly, has helped me to empathise with the participants and develop a sense of what their lives are like. Personally and professionally, I have honed the ability to engage in in-depth conversations with individuals regardless of age, status, or prior acquaintance. I have learned to listen attentively and trust my intuition to navigate interactions, whether resolving issues or understanding the core of a problem. For example, currently, I am a psychology lecturer and have had many dealings with assisting students struggling with a subject, providing an environment for them to comprehend and learn. These skills have given me the confidence to undertake this research. Additionally, my openness created a comfortable environment for participants, encouraging them to share their lives openly.

8.13 Dissemination strategy

Outputs from this study to date are:

1. Pinto, A., Rodriguez, A., Smith J**.** (2021) Researching sensitive topics in healthcare. *Evidence-Based Nursing,* 24, 41-43. https://ebn.bmj.com/content/ebnurs/25/2/41.full.pdf
2. Evidence-Based Nursing Blog (2021); Let's talk about death blogs.bmj.com/ebn/2021/06/20/lets-talk-about-death

Further dissemination strategy includes:

1. Submit the scoping review to the Journal of Death and Dying
2. Submitting the findings to the Journal of Death Studies
3. Submitting an abstract to present findings at the International Association for the Philosophy of Death and Dying annual conference (April 2025)
4. Summarise my findings for a blog post or social media content for Evidence-Based Nursing.
5. Share findings with charitable organisations within the death positivity movement.

8.14 Reflexivity

The participants in this study shared their narratives encompassing their experiences with conversations about death and dying. For some of these participants, the narratives were intertwined with their experiences of living with a life-shortening prognosis. The participants' narratives gave insight into how they lived through these experiences.

When I started this research, it was with eagerness, excitement and intermediation. I had completed a master's by research and felt the PhD journey would be much of the same. However, as I progressed through the PhD, I faced hurdles and complexities that I had not foreseen, such as accessing participants and the level of detail required at this level. I realised the importance of continuously reassessing and refining my research methods and being open to constructive criticism. This experience has taught me the value of resilience, patience and reflexivity in research. Moving forward, I will approach research with a more cautious and reflective mindset. Acknowledging the dynamic nature of the research process and the need to anticipate and address potential obstacles proactively and remain adaptable in the face of unexpected challenges or deviations from the initial research plan. This experience has highlighted the importance of continuous learning and ethical integrity in research practice, shaping my approach to future research endeavours.

In my research, I found that what I saw in the literature of the importance of structured data collection methods and systematic analysis procedures in reality was far more complex; it was messy. One aspect that stood out was the issue of participant recruitment. The literature often presents participant recruitment as a straightforward process emphasising snowball, convenience or targeted sampling strategies. However, this was different. I encountered difficulties in recruiting stakeholders to hold focus groups. Difficulties in recruiting participants who were living with a life-shortening illness. This highlighted the need for greater flexibility and creativity when adapting recruitment strategies. I had to recruit stakeholders for individual interviews. Instead of using social media as my recruitment platform, I contacted the MNDA as they support researchers and, upon approval of the content of the research, requested contact to be made with their members. This experience taught me the importance of embracing change and being flexible and creative in adapting recruitment strategies.

Furthermore, the literature portrays a linear and systematic approach to data analysis, such as coding, thematic analysis or statistical techniques. In practice, I found this to be different. I found that the analysis was messy. It was iterative, requiring constant revisiting of data and refining of coding frameworks. During the analysis, I set out to use IPA. However, I found that I needed help to keep the focus, and I was going around in so many different directions. Talking with supervisors and explaining the turmoil I appeared to be facing made it clear that I was delving into van Manen's lifeworld existentials. This experience again taught me the flexibility you must have when conducting a PhD thesis. These changes occur in many of the different stages of creating the thesis. It also taught me the value of discussing these issues with peers, as they can stop the process from being so messy and provide some clarity. What emerged through writing and reflecting on my thesis highlighted the importance of embracing methodological diversity and flexibility in research practice. This highlighted the value of integrating different methodological approaches to gain a more comprehensive and nuanced understanding of research topics, acknowledging the strengths and limitations of each approach to produce more robust and insightful research outcomes.

These discrepancies between the research methods literature I have read and the messy research reality have significant implications for my future research endeavours. I have learned the value of adaptability, resilience, and reflexivity in navigating the uncertainties and complexities of the research process. Moving forward, I will approach research with a more realistic and pragmatic mindset. I will acknowledge the inherent messiness of research and embrace it as an opportunity for growth, learning, and innovation. I will be flexible in research design and willing to engage with the messy realities of research practice to produce meaningful and robust research outcomes.

8.15 Conclusion

This thesis aimed to understand the lived experiences of death and dying conversations. Interpretations of these lived experiences have allowed for in-depth considerations about how we can foster a more death-positive culture. Highlighting the nuances of individuals' attitudes, beliefs, and emotions surrounding death and dying has supported the ethos of the death-positive movement, which advocates for open, honest, and constructive dialogue about mortality. The implications of individuals' readiness or resistance towards engaging in conversations about death and dying are significant, as they can influence their emotional well-being, coping mechanisms, and relationships with others. By amplifying these voices and experiences of the participants, I aimed to contribute to a broader societal shift towards embracing death and dying as a natural part of life, promoting empathy, understanding, and acceptance in end-of-life discussions.

This thesis has explored the potential for normalising discussions about death and dying, has shed light on individuals' existential 'Being', and uncovered diverse perspectives that shape death and dying conversations.

In conclusion, this thesis has illuminated the multifaceted nature of death and dying conversations, has empowered individuals to articulate their experiences, and advocates for a more compassionate and inclusive approach to discussing death and dying. Through reaching an in-depth understanding of individuals' lived experiences and perspectives, I have offered an adequate interpretive phenomenological representation of participants' experiences and voices. We can go on together to work towards fostering a culture that embraces death positivity and supports meaningful, authentic conversations about death, dying, and our Being toward the end of life.

Alas, *“Death is inevitable and is a universal experience” Alex Pinto, 2024*

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Appendix 1

Included study information sheet

Source	
Date of search	
Author(s)	
Title	
Aim/Hypothesis	
Study Design	
Sample Strategy	
Data Collection	
Data Analysis	
Comments	

Appendix 2

Summary table of included studies

Author, Year, Country of origin	Title	Question or Aim	Design and Methods	Sample and setting*	Key findings
Richards et al. (2020) UK	The Global Spread of Death Café: A Cultural Intervention Relevant to Policy?	Is there a relationship between DCs and broader cultural attitudes toward death and dying	Qualitative Data collected used individual and group interviews / group interviews and was analysed thematically	49 people from 34 countries NC	• There cross-cultural similarities in the perception of value of death café to support the talking about death and dying • Death café organisers were passionate about the café but there was no evidence to suggest a change in societal culture to be more open to talking about death and dying
South & Elton (2017) America	Contradictions and Promise for End-of-Life Communication among Family and Friends: Death over Dinner Conversations	To understand how groups discuss death and dying.	Qualitative Informal, unstructured focus groups. 4-8 participants at each dinner (52 dinner groups) 3 primary settings participants home, research assistant's home, public restaurant. Snowballing sampling. Constructivist grounded theory.	240 (age 18-76, 109 men, 118 women) NC	• Friend groups displayed more candidness than family groups. • Positive experience. • A need for space to have these conversations.
Waldrop et al. (2004) America	Life and death decisions: using school-based health education to facilitate family discussion	Integrating organ donation into the school curriculum. Evaluate family conversations.	Action research Four phases 1: complete pre-test surveys to assess knowledge & attitudes on organ donation.	336 pupils (ages11-18) NC	• School-based education is an effective tool. • Students felt prepared to have discussions after intervention.

	about organ and tissue donation		2: participate in a classroom presentation delivered by an educational team. 3: Students given a take-home guide and assignment to lead family discussion that focused on organ/tissue donation. 4: classroom debrief about the family discussion carried out 1 week after the initial presentation & post-test to evaluate any changes in attitudes in organ donation.		• Students found it difficult to start conversations with family – age/maturity hand an impact. • Parents of teenagers found it difficult to talk about own death.
Applebaum & Applebaum (2019) America	Families, systems, and health in our lives: A Conversation With My Personal Oncologist	Understanding of situation - A narrative between father and son regarding father's cancer.	Qualitative Interview A short narrative	2 NC	• Allowed open conversation about fear, loss and missed opportunities. • It gave some joy by listening to stories. *Though this is a snapshot into their conversation it does provide an idea that talking about D&D is beneficial.*
Schiltz et al. (2014) America	Gaining Perspective on Death: Training Program and Language Use Outcomes Assessment	An educational program exploring death and dying. The course aimed to have the individuals explore their own world views.	Mixed Intervention - 6 week distance learning course. Pre & post questionnaires/journals Content analysis T-test	30 (over 60 years of age) NC	• Positive feedback. • Deepened people's perspective towards death and dying. • More open-minded about different viewpoints of afterlife.

Margola et al. (2010) Milan/ America	Cognitive and Emotional Processing Through Writing Among Adolescents Who Experienced the Death of a Classmate	Investigating the process involved in writing about a traumatic event.	Mixed Self-reporting questionnaires repeated over 3 consecutive days. Impact of Events Scale-Revised. Students competed 3 writing sessions. Textual analysis via LIWC & T-Lab 5.1	20 Adolescents (7 boys, 13 girls, mean age 15) NC	• Insight into the process of how emotional disclosure using writing • Not all students found it helped. *No discussion about death bur written down. By writing their thoughts and feelings about a death allowed the participants to deal with their emotions. Could writing about death and dying be a way to reduce. Compartmentalised – writing could allow the individual to see their emotions, reflect and understand them.*
Zajac & Boyatzis (2020) America	Mothers' Perceptions of the Role of Religion in Parent–Child Communication About a Death in the Family	Investigate if religion shaped/was involved in the discussion about death.	Qualitative Mothers had children between the ages of 8-14. Open ended questions on Qualtrics. Thematic, deductive/inductive with several a priori themes.	21 mothers (Age 29-55) NC	• Suggestion that talking about death was beneficial to the children (emotional, social and intellectual) • Improved conversations/bond between parent & child *Shows benefits of talking about death. Hough this was following a bereavement, could the same be said to have open & frank discussions about death.*
Robinson et al. (2015) America	I Wanted You to Know: Breast Cancer Survivors' Control of Workplace Communication About Cancer	Understanding breast cancer suffers experience of support in the workplace.	Qualitative Interviews. Thematic analysis	19 full time working women who had experienced breast cancer	• Some workplaces/staff were supportive, some were not. • Interplay between attempts to maintain a sense of control in the workplace after diagnosis.

				(mean age 49.84) NC	*Companies/people who were unsupportive could it stem from their own fear?*
Ellison & Radecke (2005) America	An Undergraduate Course on Palliative Medicine and End-of-Life Issues	Educational course to demystify ageing, illness and death awareness.	Action research 28 x 1hour & 45 min sessions Students paired with a person who was approaching the end-of-life. Course evaluation questionnaires. Course teachers had evaluation questionnaires to complete. No analysis method mentioned	18 students (2-17/18 yrs., 6-16/17yrs, 7-15/16yrs, 3-13/14yrs) NC	• Positive effect on the participants. • 4 participants would not sign up again or recommend.
Thornton (1991) America	Assessment of small group discussions in a death-and-dying course	Discussion groups within a 'psychology of death and dying' unit.	Qualitative Discussions groups of 6-8 students. 6 weekly discussions Reading material and questions to be answered were provided prior to each discussion. Students anonymously completed rating scales.	29 students in spring class. 23 students in summer class. NC	• Provided structure for individuals to explore the topic of death and dying. • Majority of the students liked the group discussions. • Some groups developed strong friendships and feelings of trust.
Tieman et al. (2018) Australia	The contribution of a MOOC to community discussions around death and dying	Education activities enable people to talk and learn about death and dying.	Quantitative 1156 original enrolled. 895 participated in some way. 208 completed the learning. 4 learning modules to be completed on the social online learning platform called Open Learning.	208 people NC	• Provided a new approach to learning – community learning. • Participants were predominantly comfortable talking about D&D. • There was a willingness to discuss death and dying. • People shared experiences.

			Attitudes of participants were gathered at the time of enrolment and at the end of the course. Satisfaction was measured at 6 different time points. Descriptive statistics. Chi-squares. T-tests Mann-Whitney U Tests. Spearman’s Rank-order Correlations. Wilcoxon-Signed rank test.		
Su-Russell et al. (2021) America	Parents’ Anticipated Discussions About Death With Young Children	Exploration of how parents discussed death with their young children.	Mixed Open and closed questionnaires. Family communication orientations scale. Parents discussion of death with children, 1 qualitative question & a vignette relating to death. Multinominal logistic regression analysis. Logistic regression analysis. Constant comparative method.	112 parents (of children 3-6) NC	• Expanded understanding of family dynamic in discussing death with young children. • Parents were guided by their cultural beliefs. • Parents wanted to protect children by saying death is in the future.
Taylor (2021) UK	Transformation Through Loss and Grief: A Study of Personal Transformation	Exploring the transformational experiences following bereavement of adults.	Mixed Interviews Psychometric scales	16 people (12 women, 4 men, Ages 45-64)	• Showed positive personal change. • Endurance of adversity and suffering can be a productive and meaningful experience.

	Following Bereavement		The spiritual intelligence self-reporting inventory. The inventory of secular/spiritual wakefulness T-test Thematic Analysis	NC	
Takeuchi et al. (2021) America	Reflecting on Death Amidst COVID-19 and Individual Creativity: Cross-Lagged Panel Data Analysis Using Four-Wave Longitudinal Data	Reflection of death during Covid 19 of USA employees.	Quantitative Measures taken at four different time period's. Creativity scale. Death anxiety negative affect scale. Death reflection scale. Analysis using CLPM (cross-lagged models are a form of structural equation modelling).	605 full time employees (ages 18-77, 351 male, 254 female) NC	• Positive outcomes can come from such trying times. • Death reflection is positively related to creativity.
Hales & Hawryluck (2008) Canada	An Interactive Educational Workshop to Improve End-of-life Communication Skills	Evaluate the effectiveness of an interactive educational workshop	Quantitative 36 critical care staff took part but only 18 completed both questionnaires. Pre & Post questionnaires. McNemar test for paired categorical data	18 critical care staff. C	• Improvements found of comfort levels and confidence in 10/11 topics. • Course exceeded expectations. • Workshop excellent for improving skills. • Peer discussions were highly valued.
Llewellyn et al. (2017) New Zealand	Living into death: a case for iterative, fortified and cross-sector approach to advance care planning.	Investigating if death and dying conversations should happen earlier in life.	Qualitative Interviews Analytic approach of immersion/crystallisations	21 Adults (Age 54-65, not receiving palliative care) NC	• Engagement with the topic allowed the participant a way to meaningfully explore D&. • Helped to understand how ACP could benefit from this

Keim-Malpass (2012) America	Talking with death at a dinner: Young women's online narratives of cancer	Gain perspectives on online blogs of cancer sufferers of young women.	Qualitative Ethnography guided by hermeneutic phenomenology. Online blogs (27.4 mth average)	16 women (Ages 20-39) NC	• Understand women's narratives beyond clinical settings. • Able to express emotions. • Cathartic.
Von Blanckenburg et al. (2020) Germany	Matters of Life and Death: An Experimental Study Investigating Psychological Interventions to Encourage the Readiness for End-of-Life Conversations	Investigate different psychological interventions regarding death and dying.	Quantitative 4 different interventions Readiness to engage in EOL topics measure. Multidimensional orientation toward dying and death inventory. Patient health questionnaire PHQ-9 Participants evaluation of the intervention MANOVA ANOVA 2 week follow up.	184 (18-35 years and 65-88 years) C	• Significantly more changes in the readiness to engage in EOL discussion. • Effect remained stable at the follow-up. • Short interventions are seen to be useful for encouraging EOL discussions.
Üzar-Özçetin et al. (2020) Turkey	'Who would even want to talk about death?' A qualitative study on nursing students' experiences of talking about death with terminally ill patients with cancer	Aim to describe nursing student's experiences of talking about death with a life-shortening illness patients with cancer.	Qualitative Ethnography guided by hermeneutic phenomenology. Online blogs (27.4 mth average)	28 final year nursing students (24 women, 4 men, mean age 22.75) C	• Many of the nurses did not feel competent to talk about death with their ill patients. • They believe it is an important conversation.
Schaffer et al. (2012) America	End-of-life discussion in assisted facilities	Exploring EOL discussion from the perspectives of residents at a care home.	Qualitative Focus groups	16 residents 11 staff C	• Residents perceived family were not ready to hear about conversation on D&D.

			3 groups Residents (4-6 per group) Staff (5-6 per group) Family members (2-3 per group) TA Hamiltons contractual/community model		• Family members wanted more information regarding prognosis and care options. • Staff not feeling prepared to initiate EOL conversations. • Residents felt staff should talk about EOL.
Walczak et al. (2013) Australia/ America	Patient perspectives regarding communication about prognosis and end-of-life issues: How can it be optimised	Exploration of patients' perspectives regarding EOL and prognosis communications.	Qualitative Interviews and focus groups 8 participants for FG 11 participants interviewed Thematic Analysis	15 Australians 11 USA C	• Patients who were more expressive and sought active involvement in their care. • More likely to engage in discussion about prognosis and EOL care. • Patient also noted importance of family in prognosis and EOL discussions.
Gjerberg et al. (2015) Norway	End-of-Life care communications and shared decision-making in Norwegian nursing homes – experiences and perspectives of patients and relatives	Perspectives of nursing home residents and family re EOL conversations.	Qualitative Interviews (residents) Focus groups (family members 3-8 per group) Bricolage (one study different methods – not stated)	35 residents (Ages 68-98) 33 family members C	• Not many residents participated in EOL conversations. • Most residents wanted voice heard re medical care. • Most relatives wanted involved in conversations.
Osterlind et al. (2011) Sweden	A discourse of silence: Professional carers reasoning about death and dying in nursing homes	Exploration of the conversations of death and dying in nursing homes.	Qualitative Focus groups (5 groups) Discourse (interpretative process rather than step by step)	28 staff (Ages 20-64) C	• Death is silent and silenced. • Death s pushed away. • Staff's emotions ignored. • Need to see dying as a process.
Clarke & Ross (2006) UK	Influences on nurses' communications with older people at the end-of-life: perceptions and	Perception of the medical staff of listening and talking to dying older people about EOL.	Qualitative Focus groups (4 groups)	24 Medical staff C	• Staff wanted to communicate with dying older people but need more support to be able to do this.

	experiences of nurses working in palliative care and general medicine.		Constant comparative technique		• Doctors and family tended to shield older people from their full diagnosis.
Bloomfield et al. (2015) UK	Enhancing student communication during end-of-life care: A pilot study	Design, implementation, & evaluation of a communication intervention for medical students.	Mixed Focus groups used to explore the students' experiences of communication with dying patients and their families (3 groups with medical students & 2 groups with nursing students). Development of teach course (scenarios with actors) and questionnaires. Pre-questionnaires/intervention/post-questionnaires. Descriptive statistics & the Wilcoxon test. Thematic analysis.	19 Medical students p in the focus groups. 27 medical students in the simulated teaching sessions. C	• Simulation scenarios were effective as a way of learning. • Emphasis that training medical personal in the pre-qualification stages. *Could be extrapolated further and death conversations at schools/colleges/universities*
Kennedy & Williams (2009) UK	Information and communication when a parent has advanced cancer	Exploration of children's information needs. Understanding barriers that may exist that stop the child from accessing information	Qualitative Interviews. Constructionist grounded theory.	28 participants made up of 7 families inc children. 10 ill parents. 7 main carers. 11 children C	• Children wanted honest information about parents' health. • Wanted information from various sources. • Wanted access to someone they can talk to. *Improving communication within and outside family would be beneficial.*

Wiener et al. (2008) UK	How I Wish to be Remembered: The Use of an Advance Care Planning Document in Adolescent and Young Adult Populations	Exploration of adolescent's perspectives on planning documents of their wishes/thoughts regarding EOL care.	Qualitative Interviews Evaluation of 5 wishes document. Descriptive statistics used.	20 participants (Age 16-25 with HIV or cancer diagnosis) C	• Found the documents helpful. • Participants more interested in how they wanted to be treated and remembered rather than medical decision-making.
Willig (2015) UK	"My Bus Is Here": A Phenomenological Exploration of "Living-With-Dying"	To gain an understanding of what it is like to live whilst knowing that you have a life-shortening disease.	Qualitative Interviews. Hermeneutic phenomenology.	10 Participants with advanced metastatic cancer C	• People who are dealing with their death are able to talk to someone about the chaos' they were feeling. • Wanted to talk about negative as well as the positive in a safe place, no judgement and no one trying to move the conversation away from the negative. *Though this study didn't have any conversations directly about D&D, it was about the individuals who are facing their imminent death and how they saw their life, what they did and how they live and to be able to talk both positively and negatively about D&D.*
Kars et al. (2015) Netherlands	The Parents' Ability to Attend to the "Voice of Their Child" With Incurable Cancer During the Palliative Phase	To understand what difficulties parents face trying to give a voice to their ill child.	Qualitative Interviews. Complimentary intertwined strategies – coding and thinking theoretically. Sounds as if it could be Grounded theory	34 participants (34 parents of 17 children with incurable cancer with age ranges 9	• Parents had difficulty in gaining insight into their child's perspective. • Parents used direct and indirect strategies to attempt to understand child's perspective. • Parents avoided direct conversations with their child to protect the child.

				months-18 years) C	
Bartels & Faber-Langendoen (2001) America	Caring In Crisis: Family Perspectives on Ventilator Withdrawal at the End-of-life	Understanding the family’s perspective on the removal of the ventilator.	Qualitative Interviews. Inductive Analysis? Thematic Part of a larger study	21 participants (9 spouses, 4 children, 5 families with more than one member participating in the study) C	• Clear communication from medical staff helped families. • Families did expect Drs. to talk through the dying process. *Need to be more open about the actual death process before the actual time.*
William-Reade et al. (2018) America	Enhancing Residents’ Compassionate Communication to Family Members: A Family Systems Breaking Bad News Simulation	Improving residents’ communication with families.	Mixed 8 2hr educational seminars Survey completed at 3 different time points (before seminars, after the training and 6 months follow-up) Questionnaire regarding preparation, skills confidence and anxiety about engaging along with open questions. Measure to evaluate different aspects of SPIKES. T-tests. Thematic analysis for open questions.	15 participants (paediatric surgery residents) C	• Increased confidence & skills in communicating difficult information to families. • Effect reduced back to base line after 6 months. *This communication teaching could be extrapolated to communication in general to improve D&D conversations, help with creation of intervention or educational tool.*
Silverman & Worden (1992)	Children’s reactions in the early months	Understand children’s reactions to the death of a parent.	Mixed Interviews & surveys	70 families with 125 children	• Children wanted to stay connected with deceased parent by talking about them

America	after the death of a parent		Child behavior checklist Perceived competence scale for children Locus of Control Scale Descriptive statistics & T-tests	(65 boys, 60 girls, aged between 6-17 years. 74% lost a father, 26% lost a mother) C	not necessarily talking about their feelings. • 17% of children displayed significant problem behaviour in the first few months after death. • 83% of the children carried on. *Talking about deceased could be seen as coping mechanism. Could more open discussion about death have helped?*
Cherlin et al. (2005) America	Communication between Physicians and Family Caregivers about Care at the End-of-life: When Do Discussions Occur and What Is Said?	Doctors communicate about incurable illness, life expectance, hospice and timings of discussions.	Mixed Surveys (6 survey questions) Interviews. Frequency analysis. T-test. Constant comparative method	218 family caregivers 12 interviewed C	• Some doctors never told caregivers patients illness could not be cured or gave life expectancies. • Drs never discussed hospice.1st discussion was about 1 moth prior to death. • Caregivers' difficulty comprehending and accepting bad news.
Oosterveld-vlug et al. (2016) Netherlands	How should realism and hope be combined in physician–patient communication at the end-of-life? An online focus-group study among participants with and without a Muslim background	Exploration of patients, relatives, and healthcare professionals with/without Muslim background.	Qualitative 24 (patients, older people, relatives without a Muslim background, 13 male, 11 female, 22 from Netherlands, 2 form Indonesia, Ages 40-80) 21 (healthcare professionals without a Muslim background, 7 male, 14 female, 20 from Netherlands, 1 form Indonesia, Ages 24-72)	54 participants C	• Participants preferred that doctors provide realist information, but in an empathetic way. • Want to know how they can be helped during their remaining time.

			9 (patients & relatives with a Muslim background 7 male, 2 female, 3 from Turkey, @ from Morocco, 1 from Afghanistan, 1 form Surinam, 1 from Indonesia, 1 form Netherlands, age 31-66). Online focus groups. Thematic Analysis		
Van der Geest et al. (2015) Netherlands	Talking about Death with Children with Incurable Cancer: Perspectives from Parents	To understand the rationale and consequences of a parent's decision to talk about death with their child with incurable cancer.	Qualitative Retrospective study. Time between child's death and completion of questionnaires was between 3-8 years. Open ended questionnaires (with some descriptive statistics). Framework analysis.	86 parents (54 mothers, 32 fathers) of 56 terminally ill children C	• 55 parents of 35 children did not talk about the impending death because of: Inability to discuss. Desire to protect their child. Child unwilling to discuss. Lack of opportunity to talk. • Parents who did talk used symbolic &/or religious narratives, had brief talks. • Most parents felt positive regarding their decision whether or not to talk to their child about their death.
Piers et al. (2013) Belgium	Advance Care Planning in terminally ill and frail older persons	Understanding the views of elderly patients on ACPS.	Qualitative Interviews. Framework analysis.	38 elderly patients with limited prognosis (age 71-104) C	• Majority wanted to talk about dying, whilst a few did not. • Most wanted to plan EOL care relating to personal experiences or their fears.
Malcomson & Bisbee (2009) America	Perspectives of healthy elders on advance care planning	Exploration of the perspectives of health elders on ACP.	Qualitative Focus groups (4 groups). Content analysis.	20 healthy older people (age 60-94) C	• Elders assumed family knew their wishes. • More prepared for the death rather than the process. • Believe ACP should be done whilst relatively healthy.

Cassano et al. (2008) Canada	Talking With Others Who "Just Know": Perceptions of Adolescents With Cancer Who Participate in a Teen Group	Exploration of adolescents' perception of teen support groups.	Qualitative Interviews. Purposeful sampling. Constant comparative method.	11 cancer patients (age 14-20) C	• Able to talk to other teens who understand. • Having fun as a normal teenager. • Being able to deal with the death of group members.
Coyle (2006) America	The Hard Work of Living in the Face of Death	Exploring individual's experience of living with cancer.	Qualitative Interviews Interpretive Phenomenology	7 adults living with advanced cancer (age 40-79) C	• Difficult to understand their disease and its implications. • Patients search for and creating a safe and supportive system. • Struggle to find meaning and create a legacy.
Nellis et al.(2016) America	The Use of Simulation to Improve Resident Communication and Personal Experience at End-of-Life Care	Understanding the use of simulations to help improve communication skills.	Quantitative Quasi experimental 12 residents in intervention group. 19 residents in control group. Pre: Self-perceived assessment of competency (assessing exposure to EOL care & perceived abilities). Simulations (groups of 2 focus on EOL care & communication) Kravit Retreat Assessment & Communications (checklist & audiotapes) Post: same questionnaire as pre. Wilcoxon signed-rank test	31 paediatric residents. C	• Residents perceived themselves to be more capable of informing family of death after taking part in the simulations.

Johnson & Bott (2016) America	Communication With Residents and Families in Nursing Homes at the End-of-life	Investigation into who communicates with family about death and dying.	Quantitative Descriptive secondary analysis. 4 items for 1 subconstruct planning/intervention of the palliative care practice construct of the Palliative Care Process Measure. Analysis of variance to test for differences. between the three groups. RNs (registered nurses), LPNs (licences practical nurses), unlicensed staff.	2191 direct care staff (from 180 care facilities, ages 18-65) C	• Conversations occur when direct staff feel confronted to do so. • Staff felt doctors or social workers should talk about death and dying with the family
Au et al. (2012) America	A Randomized Trial to Improve Communication About End-of-Life Care Among Patients With COPD	Assess an intervention using patient-specific feedback regarding EOL care.	Quantitative Stratified randomised sampling. 155 patients in control group, 151 in the intervention group. Baseline questionnaires: Quality of Communication (QOC) questionnaire. The Preferences for Dying and Death questionnaire. The St. George Respiratory Questionnaire. Preferences for communication about end-of-life care and patient-specific barriers and facilitators to this communication. Preferences for life-sustaining treatments. Socio- demographic information.	92 clinicians 306 patients with COPD C	• Patients with intervention reported higher numbers of EOL care discussions. • Higher quality discussion with intervention.

			I page Intervention designed to increase self-efficacy regarding discussion of death and dying. Resurveyed 2 weeks after intervention. Intention to treat regression analysis.		
Chiu et al. (2012) Taiwan	Communication online with fellow cancer patients: Writing to be remembered, gain strength, and find survivors	Exploration of internet use through a person's illness.	Qualitative Focus groups Ground approach analysis	34 cancer patients. NC	• By writing blogs patients were able to reconstruct their life story. • Reading other blogs had a greater influence of their prognosis than that of a doctor's influence. • It was a way for cancer patients to create something for their family to remember them by after their death. • Therapeutic benefits for patients using the internet platform.
Nedjat- Haiem et al. (2016) America	Exploring Health Care Providers' Views About Initiating End-of-Life Care Communication	Exploring barriers, and perceptions of the medical and non-medical staff regarding EOL care communication.	Qualitative Interviews Stratified purposive sampling.	25 doctors (17 male, 8 female) 17 social workers (5 male, 12 female) 23 nurses (2 male, 21 female) 14 chaplains (10 male, 4 female)	• Highlighted the importance of starting EOL discussion early by doctors because of medical training. • Highlights interdisciplinary approach involving all four categories.

				C	
Li et al. (2023) China	Effects of online-offline integrated death education on patients with advanced cancer: A before and after study.	Evaluation of the effectiveness of online/offline integrated death education of patients with cancer	Mixed Interviews Pre-interview questions Measures – LAPS, FACIT-Sp12, FDAS, OOIDE satisfaction survey T-tests, Pearson chi-square Possibly grounded theory	32 patients with advanced cancer (18 male & 14 female, age range 41-86) C	• OOIDE improved overall attitudes towards life. • Death anxiety decreased following OOIDE. • Improved spirituality. • Facilitated EOL preparations
Bartlet et al. (2022) America	Characterizing the language used to discuss death in family meetings for critically ill infants	Characterise the way death is discussed in family meetings. How death discussions differ between clinicians and family members	Qualitative Content analysis with descriptive statistics Used recordings of family meetings from a larger study.	68 Family meetings 36 parents of 24 infants. C	• Clinicians tended to use medical jargon. • Families used colloquialisms for death. • Euphemisms can leave room for misunderstandings.
Henderson et al. (2023) America	Mortality conversations between male veterans and their providers prior to dysvascular lower extremity amputation	Gain an understanding of patient & provider experiences discussing mortality with the context of amputation	Qualitative Interviews Deductive/inductive content analysis	22 patients (age range 40-89); 21 surgeons & Drs (12 male, 9 female) C	• Mortality conversations not common. • Medical staff find value in mortality conversations, but express concern in engaging in these types of conversations with patients. • Some patients see mortality conversations as unnecessary but many are open to engaging in the conversations.

**NC – non-clinical setting   C – Clinical setting*

Appendix 3

Study characteristics tables

Geographic locations

Country	America	UK	Denmark	Australia	New Zealand	Belgium	Canada	Milan/America
Number of studies	25	7		1	1	1	2	1

Country	Australia/ America	Norway	Germany	Turkey	Sweden	Netherlands	Taiwan	China
Number of studies	1	1	1	1	1	3	1	1

Participant characteristics

Participant characteristics	Adults	Health professionals	Children/ Adolescents	Dealing with a medical illness	Veterans
	11	6	1	11	1

Participant characteristics	Mothers only	People in remission	Students	Parents of ill children	Residents & Medical staff	Nursing care patients & Families
	1	2	6	6	1	1

Clinical settings

Settings	Clinical	Non-Clinical
Number of articles	30	17

Search methods

Types of methods	Quantitative	Qualitative	Mixed	Action Research
Number of articles	7	29	9	2

Data collection methods

Data Collection Method	Interviews	Surveys or questionnaires	Online blogs	Focus groups	Recordings
Number of articles	20	23	2	11	1

Data analysis methods

Data Analysis	Thematic Analysis	Stats	Content	GT	Constant Comparative Method	Narrative
Number of articles	10	16	5	6	4	1

Data Analysis	Hermeneutic or interpretive phenomenology	Discourse	Framework Analysis	No analysis mentioned	Others
Number of articles	3	1	2	4	6

Appendix 4

Interview guides

Not living with a life-shortening Illness interview guide

Item	Approx. Timings
Introduction of the interviewer	5 mins
Consent and confidentiality for digital recording of the interview & explanation of participants’ rights	
Outline the procedure and definition of death/dying conversation and death positivity movement	
Explain withdrawal and timeframes and that they do not have to answer a question if they do not wish to.	
Could we start by talking a little about yourself? *Prompts: What do you do? How long? Your beliefs?*	55 mins
Could you describe your experiences of talking about death/dying? *Prompts: What helped you talk about death/dying? What makes it difficult to talk about death/dying? Any experiences of hostility regarding death/dying conversations?*	
What does talking about death/dying mean to you? *Prompt: Why was this conversation so memorable do you think?*	
Do your peers/family share your views about death/dying conversations? *Prompts: Can you provide examples? Why was this example memorable to you?*	
How has COVID affected your conversations about death/dying?	
Prompts: Can you provide examples?	
Can you tell me more about whether you intend to take part in death/dying conversations/activities? *Prompts: How? When? With whom? Why?*	
What could be done to encourage death/dying conversations	
Is there anything we are forgetting, anything we have not said with respect taking part in or discussing death/dying? Anything more that you would like to share/discuss?	5 mins

Living with a life-shortening illness interview guide

Item	Approx. Timings
Introduction of the interviewer	5 mins
Consent and confidentiality for digital recording of the interview & explanation of participants’ rights	
Outline the procedure and definition of death/dying conversation and death positivity movement	
Explain withdrawal and timeframes and that they do not have to answer a question if they do not wish to.	
Could we start by talking a little about yourself? *Prompts: What do you do? How long? Your beliefs?*	55 mins
Tell me about your prognosis journey? *Prompts: What does this experience mean to you? How has it affected your life?*	
Could you describe your experiences of talking about death/dying? *Prompts: What helped you talk about death/dying? What makes it difficult to talk about death/dying? Any experiences of hostility regarding death/dying conversations?*	
What does talking about death/dying mean to you? *Prompt: Why was this conversation so memorable do you think?*	
Do your peers/family share your views about death/dying conversations? *Prompts: Can you provide examples? Why was this example memorable to you?*	
How has COVID affected your conversations about death/dying? *Prompts: Can you provide examples?*	
Can you tell me more about whether you intend to take part in death/dying conversations/activities? *Prompts: How? When? With whom? Why?*	
What could be done to encourage death/dying conversations	
Is there anything we are forgetting, anything we have not said with respect taking part in or discussing death/dying? Anything more that you would like to share/discuss?	5 mins

Focus group interview guide

Item	Approx. Timings
Introduction of the facilitator/moderator/discussion	5 mins
Consent and confidentiality for digital recording and of the focus group, explanation of participants' rights	
Outline the procedure for the focus group.	
Explain withdrawal and timeframes and that they do not have to answer a question if they do not wish to.	
Could we start by briefly telling me your understanding of what Death Positivity means? *Prompts: What does it mean to you?*	60 mins
In general, do you think people engage in enough conversations about death and dying? *Prompts: If yes/no, why? Can you provide examples? Why was this example memorable to you?*	
What are your experiences of talking about death and dying? *Prompts: What helps when talking about death/dying? What makes it difficult to talk about death/dying? Describe any hostility experienced when talking about death/dying*	
What does talking about death/dying mean to you? *Prompt: Why was this conversation so memorable do you think?*	
Do your peers/family share your views about death/dying conversations? *Prompts: Can you provide examples? Why was this example memorable to you?*	
What could be done to encourage death/dying conversations *Prompts: Education? What age?*	
How has COVID affected your conversations about death/dying? *Prompts: Can you provide examples?*	
Is there anything we are forgetting, anything we have not said with respect to supporting people to take part in/organise or initiate death dying conversations? Anything more that you would like to share/discuss?	5 mins

Appendix 5

Focus group private message wording

Focus Group Twitter wording

I am contacting you as you are involved in promoting a more positive perspective towards death and dying. You have encouraged people to have more open discussions about death and dying.

I am a PhD student at the University of Leeds and am undertaking a study to explore the conversations people have regarding death and dying. Ethical approval has been given from the School of Healthcare Research Ethics Committee (SHREC project Number HREC 20-024)

I would like to ask if you would be interested in attending a focus group to discuss your perception of death/dying conversations. It would involve attending a focus group with approximately 6-8 people, and discussing death/dying conversations. If you are interested, please provide me with an email address, and I will send you an invitation, along with documentation for you read to help you decide if you wish to take part.

I look forward to hearing from you.

Appendix 6

Focus group formal email invitation

Dear

Thank you for your interest in my research and providing me with your email address.

I would like to formally invite you to take part in a focus group with other people to discuss how we can make death/dying less of a taboo subject.

The majority of people do not discuss death /dying until there is a medical reason to do so, and most of the conversations are held within a clinical setting. My research will be exploring people's perceptions of death/dying conversation, with the aim to consider what could be done to help facilitate open conversations about death/dying, outside of clinical settings.

I have included a copy of the information sheet, for you to keep. This sheet details the aims and methods of the study as well as your role. I would be grateful if you could read this information before you decide to make your decision. If you decide to participate in the research, please complete the attached consent and demographic forms and return to me as soon as possible. An electronic or typed signature will suffice.

Taking part in the study would involve being part of a focus group of between 6-8 people, for approximately 1 – 1.5 hours. The focus group discussion would be undertaken on-line via the web conference platform called Zoom. If you have never used Zoom, I can provide you with instructions to access it and how to use it. If you need to, we can arrange a test meeting to make sure you know how the platform works.

To take part in the study you must be over 18 years of age, be able to speak/read English (or work with a carer who does), have access to the internet/smart phone technology, be employed or run a death positivity group/website and provide informed consent.

Ethical approval has been given for this study from the School of Healthcare Research Ethics Committee (SHREC project Number HREC 20-024)

In addition, I would also be grateful if you would be able to advertise the study on your websites or post information via your twitter accounts to recruit adults who have taken part in any events that you may have organised. These individuals include those who have a terminal prognosis, have no terminal prognosis, or are bereaved. I attach a copy of the proposed advert. Please let me know if you have any questions.

Furthermore, if you require any further information regarding this study and your role as a participant, please contact me on my email and I will be happy to answer any questions you may have.

Thank you for showing an interest in my research and I look forward to hearing from you.

Kind regards,

Alex

Alex Pinto
hcapp@leeds.ac.uk

Appendix 7

Focus group participant information sheet

Project Title: Exploration of lived experiences of death and dying conversations: A phenomenological study.

Researcher: Alexandra Pinto

Supervisors: Dr Alison Rodriguez and Dr Joanna Smith

Invitation
I would like to invite you to take part in my doctoral research study. To help you decide whether to take part in the study, I would like you to understand why this research is being done and what it would involve for you. If there is anything that is not clear, or you would like more information please contact me by email, hcapp@leeds.ac.uk. Kind Regards, Alex Pinto.

What is the purpose of the study?

The overall purpose of this study is to explore individuals' perceptions and lived experiences of death and dying conversations. Death is an absolute reality, but conversations around death and dying are often avoided unless individuals are recently bereaved or facing a terminal prognosis.

Objectives of the study

- I will be exploring the motivations and experiences of individuals who are involved with the death positivity movement.
- I aim to understand the content and impact of death and dying conversations and events experienced and facilitated by the death positivity movement.
- I will explore if the global pandemic of COVID has influenced individuals' experiences, perceptions and death and dying conversations.

Why am I being asked to take part?

The Death Positivity movement is considered a social and philosophical movement that encourages people to have open and frank discussions about death and dying. You have been contacted because you have been identified as a professional/individual involved in work that can be associated with the death positivity movement. As such, your perceptions and experiences of the death positivity movement and influences on death and dying conversations will be valuable.

What will happen if I decide to take part?

Please read the University of Leeds Privacy Notice for Research along with this form, and if you wish to take part, you need to return the consent form (with electronic signature) and demographic forms to me, Alex Pinto at hcapp@leeds.ac.uk. Once confirmation is received that you wish to take part, I will contact you to invite you to a focus group discussion, if a focus group date was not convenient then there would be the option for you to instead undertake a one-to-one interview. This would occur within 4-5 weeks. Due to COVID and geographical restrictions, for your safety and convenience, the focus groups/interview will be online via Zoom. You will be sent a weblink via email so that you can take part. The focus group discussion will last approximately one to one and a half hours. During the focus group we will explore motivations for and experiences of involvement within the death positivity movement. You do not have to share anything with the group that you are not comfortable in sharing. As a participant you will be advised that the meeting will be audio and video recorded, and the confidential nature of the group outlined. After the focus group/interview, the recording will be labelled with a number and each participant will be given a pseudonym (false name). Each focus group will be typed up, but no participant will be identifiable in the transcript

Do I have to take part?
You do not have to take part in the study. It is entirely up to you whether you want to take part. If you decide to take part, this information sheet is for you to keep. You will also be sent via email, a consent form for you to sign. You must only sign if you agree that you understand the purpose of the study and that you wish to take part in the focus group and to the recording of the information collected. You will be asked to agree to me taking notes and using direct quotes from your focus group/interview in my thesis and publications. It will be ensured that you are not identified. You will also need to be in a safe, private space that will allow you to talk freely about death and dying. Before the focus group/interview starts you will be asked again if you wish to take part, and agree to video and audio recorded. There will be the option to turn off your camera if you wish.

What will happen if I do not want to carry on with the study?
If you decide not to take part in the study after you have initially agreed, you can withdraw without any obligation to provide a reason. If you decide to leave the focus group/interview, you can do so without giving a reason. If you decide to leave the study after the focus group/interview has taken place and within two weeks following your focus group discussion/interview, your data on transcripts will be made void. However, if you decide to leave after your focus group/interview has been analysed, your contribution cannot be removed. If you do want to withdraw from the study, please contact me on hcapp@leeds.ac.uk.

How will my privacy be protected?
All information that is collected as part of this study will be kept strictly confidential and stored without any identifying details under secure conditions. However, if a disclosure is made that indicates that the participant or someone else is at serious risk of harm. Such disclosures may be reported to the relevant authorities.

You will be asked for permission to audio and video record the focus group/interview. The video recording is not needed and will be deleted. However, the audio recordings will be kept in a password protected file on the M-Drive of the University of Leeds secure server and will be destroyed once they have been transcribed. 1st Class Secretarial will also have access to the audio files for transcription purposes and have signed confidentiality agreements with the University of Leeds.

You will be asked to maintain confidentiality of the information discussed during the focus group and not disclose the names of other participants involved without their prior agreement.

Transcripts of the focus group/interview will be anonymised and kept as password-protected electronic files on the M-Drive of the University of Leeds secure server. Any quotes used in the dissemination of the research, will not include any identifying information. All participants will be given a pseudonym (false name). Only myself and my research supervisors will have access to the anonymised data, and they will not share this information with anyone. However, excepts from the anonymised transcripts will be used in my thesis and related publications.

What will happen following the study?

Once all the data has been collected, the focus group/interview recording will be transcribed and anonymised, and I will undertake various analyses. I can share the results with you. If you wish me to do this, please provide your email address following the focus group discussion/interview. The findings will be written into a PhD Thesis and will be published in relevant health and social care journals. No participants will be identified in any publication. Transcribed data will be kept within a password-protected file on the M-Drive of the University of Leeds secure server until the point of publication. Data generated during the research will be retained in accordance with the University's Data Protection Policy.

What are the possible benefits and risks of taking part in this study?

If you decide to take part, we hope it will be enjoyable. Your contribution is valuable. There are no anticipated or known risks. Everything you share as part of your participation is voluntary, and if at any point you feel you would prefer to stop, or would prefer not to share something, that is fine. You are free to decline to answer any question that makes you feel uncomfortable. In the focus group discussions/interview, you might want to talk about your experiences with individuals, friends or relatives at the end-of-life. While some people find it helpful to talk about their experiences to researchers this is not the same as counselling. However, I can provide you with a list of how to get further support/counselling support if you want. It is highly unlikely you will suffer harm by taking part.

Who has reviewed the study?

Ethical approval has been given from the School of Healthcare Research Ethics Committee (SHREC project Number HREC 20-024). The University adheres to its responsibility to promote and support the highest standards in all aspects of research. If you wish to make a complaint about any aspect of the study, please contact Ms. Clare Skinner, Head of Research Integrity and Governance, Secretariat, University of Leeds via email: c.e.skinner@leeds.ac.uk

Who is organising and funding the study?

This study is being undertaken as part of a PhD (Doctoral) programme of study at the University of Leeds.

Who can I contact for further information?

Hopefully, this information sheet has told you what you need to know before deciding whether to take part. If you have any queries about this study, please contact the researcher, Alex Pinto (hcapp@leeds.ac.uk) or my supervisors Dr Alison Rodriguez (a.m.rodriguez@leeds.ac.uk) and Dr Joanna Smith (j.e.smith1@leeds.ac.uk) from the University of Leeds.

Thank you for considering to take part in this study.

Appendix 8

Focus group consent form

Consent to take part in the Exploration of lived experiences of death and dying conversations: A phenomenological study.	Add your initials next to the statement if you agree
I confirm that I have read and understand the information sheet V2.3 8 April 2022 explaining the above research project and I have had the opportunity to ask questions about the project.	
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. In addition, I understand that if I wish to remove any of my data following the focus group/interview, I can do so within 2 weeks of attending the focus group. (Please contact Alex Pinto via email: hcapp@leeds.ac.uk	
I understand that the focus group/interview will be audio and visually recorded.	
I understand that members of the research team may have access to my responses. I understand that my interview recording will be accessed by a third party (1st Class Secretarial) for transcription purposes only. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.	
I understand that the data collected from me may be stored and used in relevant future research in an anonymised form.	
I understand that relevant sections of the data collected during the study, may be looked at by individuals from the University of Leeds or from regulatory authorities where it is relevant to my taking part in this research.	
I agree to take part in the above research project and will inform the lead researcher should my contact details change.	
I agree to maintain the confidentiality of the information discussed during the focus group/interview and I will not disclose the names of others involved without their prior agreement. (If you cannot agree to this stipulation, please contact the researcher as you may be ineligible to participate in the study.)	
I am aware that confidentiality cannot be maintained if issues suggesting unsafe practice, negligence or criminality are raised.	
I would like to be informed of the study results.	

Name of participant	
Participant's signature	

Date	
Name of lead researcher	Alexandra Pinto
Signature	
Date	

Appendix 9

Demographics form

Participant ID:

Participant Age:

At birth, you were described as (These categories of gender follow the guidelines from the Equality and Human Rights Commission)

○ Male
○ Female
○ Intersex
○ I'd prefer not to say

Which of the following describes how you think of yourself?
(These categories of gender follow the guidelines from the Equality and Human Rights Commission)

○ Male
○ Female
○ Intersex
○ I'd prefer not to say

What is your highest level of education achieved so far?

○ No formal qualifications
○ GSCE's or equivalent
○ AS/A Levels or equivalent
○ Bachelor's degree or equivalent
○ Master's degree or equivalent
○ Professional degree
○ Doctoral degree
○ Trade/technical/vocation training not listed above (please describe below)
○ Other (please describe below)
○ I'd prefer not to say

If you answered "trade/technical/vocational" or "other" to the previous question, please describe here:

What is your occupation?

Appendix 10

Research participant privacy notice

Purpose of this Notice

This Notice explains how and why the University uses personal data for research; what individual rights are afforded under the Data Protection Act 2018 (DPA) and who to contact with any queries or concerns.

All research projects are different. This information is intended to supplement the specific information you will have been provided with when asked to participate in one of our research projects. The project specify information will provide details on how and why we will process your personal data, who will have access to it, any automated decision-making that affects you and for how long we will retain your personal data.

Why do we process personal data?

As a publicly funded organisation we undertake scientific research which is in the public interest. The DPA requires us to have a legal basis for this processing; we rely upon “the performance of a task carried out in the public interest” as our lawful basis for processing personal data, and on “archiving in the public interest, scientific or historical research purposes, or statistical purposes” as our additional lawful basis for processing special category personal data (that which reveals racial or ethnic origin, political opinions, religious or philosophical beliefs, trade union membership, genetic or biometric data, and data concerning health, sex life or sexual orientation).

How do we follow data protection principles?

- We have lawful bases for processing personal and special category data.
- Data are used fairly and transparently; we will make it clear to individuals what their data will be used for, how it will be handled and what their rights are.
- We only collect and use personal data for our research, for research in the public interest, or to support the work of our organisation.
- We only collect the minimum amount of personal data which we need for our purposes.
- We take steps to ensure that the personal data we hold is accurate.
- We keep your personal data in an identifiable format for the minimum time required.
- We take steps to ensure that your data is held securely.
- We keep a record of our processing activities.

What do we do with personal data?

Research data can be a very valuable resource for improving public services and our understanding of the societies we live in. One way we can get the most benefit from this work is to make the data available, usually when the research has finished, to other researchers. Sometimes these researchers will be based outside the European Union. We will only ever share research data with organisations that can guarantee to store it securely. We will never sell your personal data, and any data shared cannot be used to contact individuals.

The project specific information will include more detail about how your data will be used.

Your rights as a data subject

Because we use personals data to support scientific research on the public interest, individuals participating in research do not have the same rights regarding their personal data as they would in other situations. This means that the following rights are limited for individuals who participate, or have participated in, a research project:

- The right to access the data we hold about you.
- The right to rectify the data we hold about you.
- The right to have the data we hold about you erased.
- The right to restrict how we process your data.
- The right to data portability.
- The right to object to us processing the data we hold about you.

Data security

We have put in place security measures to prevent your personal data from being accidentally lost, used or accessed in an unauthorised way and will notify you and any applicable regulator of a suspected breach where we are legally required to do so.

Retention periods

We will only retain your identifiable personal information for as long as necessary to fulfil the purposes we collected it for; we may then retain your data in anonymised or pseudonymised format.

To determine the appropriate retention period for personal data we consider the amount, nature, and sensitivity of the personal data, the potential risk of harm from unauthorised use or disclosure, the purposes for which we process your personal data and whether we can achieve those purposes through other means, and the applicable legal requirements.

Additional notices and guidance/policies

The University has also published separate policies and guidance which may be applicable to you in addition to other privacy notices:

Current staff privacy notice
Current students privacy notice

The Research and Innovation Service website has other relevant policies and guidance.

Communication

In the first instance please contact the researcher who your initial contact was with. You may also contact the Data Protection Officer for further information (see contact details below).

Please see the Information Commissioner’s website for further information on the law.

You have a right to complain to the Information Commissioner’s Office (ICO) about the way in which we process your personal data. Please see the ICO’s website.

Concerns and contact details

If you have any concerns with regard to the way your personal data is being processed or have a query with regard to this Notice, please contact our Data Protection Officer (Alice Temple: A.C.Temple@leeds.ac.uk).

Our general postal address is University of Leeds, Leeds LS2 9JT, UK.

Our postal address for data protection issues is University of Leeds Secretariat, Room 11.72 EC Stoner Building, Leeds, LS2 9JT.

Our telephone number is +44 (0)113 2431751.

Our data controller registration number provided by the Information Commissioner's Office is Z553814X.

This notice was last updated on 20 February 2019.

Appendix 11
Zoom instructions

Zoom Instructions

You do not need to have a webcam/camera to be part of this research study, the interview can be conducted using the microphone only. Prior to the start of the interview, I will ask your permission to record and continue with the interview.

Before the meeting you are able to download the Zoom app to your computer or smart phone. The link for this is: https://zoom.us/download and follow the instructions to install.

In the email invite there will be a link to the meeting. Click on the link.

Join Zoom Meeting

https://zoom.us/j/8621790168?pwd=L3QyWStQSEJDZlBNTGlhc3J0V05qdz09

Meeting ID: 862 179 0168

Passcode: jEs7gx

One tap mobile

+13126266799,,8621790168#,,,,*543239# US (Chicago)

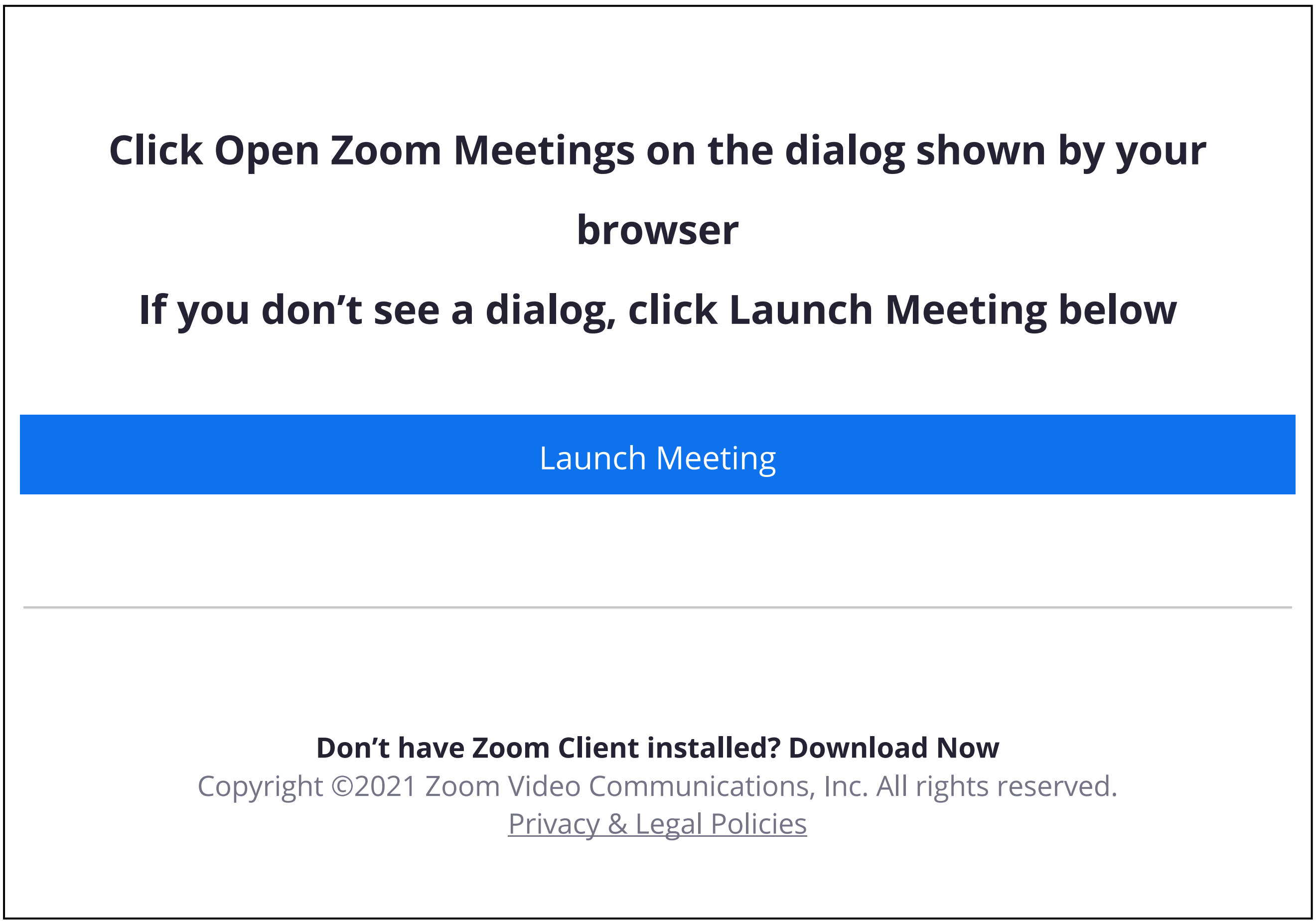
+13462487799,,8621790168#,,,,*543239# US (Houston)

Dial by your location

+1 312 626 6799 US (Chicago)

+1 346 248 7799 US (Houston)

When you click the link, you will get this:



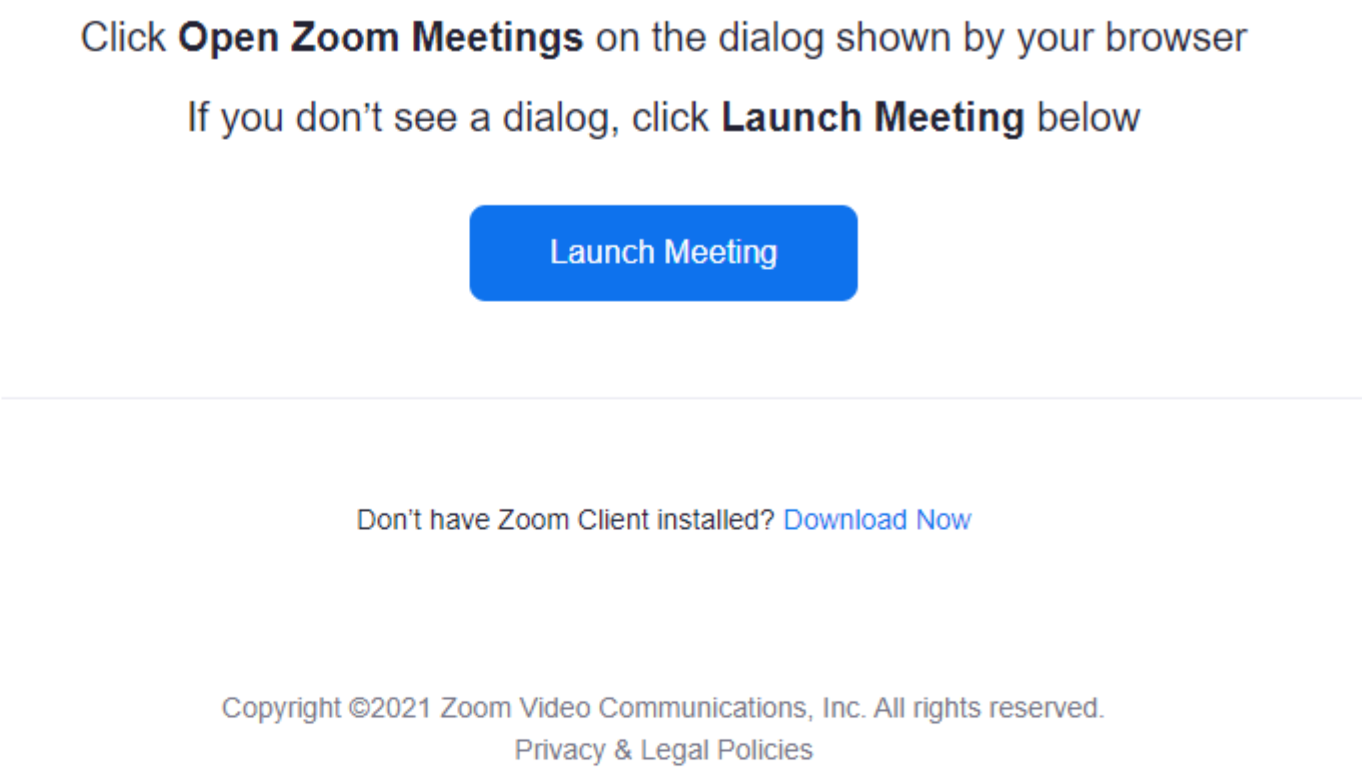
Click Open Zoom Meetings on the dialog shown by your browser

If you don’t see a dialog, click Launch Meeting below

Don’t have Zoom Client installed? Download Now

Copyright ©2021 Zoom Video Communications, Inc. All rights reserved.

Privacy & Legal Policies



Click **Open Zoom Meetings** on the dialog shown by your browser

If you don't see a dialog, click **Launch Meeting** below

Don't have Zoom Client installed? Download Now

Copyright ©2021 Zoom Video Communications, Inc. All rights reserved.
Privacy & Legal Policies

If you have used Zoom before, then click on **Launch Meeting**, if not then click on **Download Now**.

Click on **Join with Computer Audio**, which will allow you to use your computer's audio system. You will then have video and audio capabilities.

In the left-hand corner of the Zoom window is the mute and video icons. If you need some privacy then you can unmute/mute your microphone and stop/start your video. If you wish to leave the meeting you click the red end button, you will be asked to confirm that you wish to leave.

Appendix 12

Debrief form

Working Title: Exploration of lived experiences of death and dying conversations: A phenomenological study

Name of Investigator: Alexandra Pinto

Thank you very much for taking part in this study. I appreciated your time and interest.

Please keep the information discussed during the focus group or any names of others who participated confidential.

Participating in this focus group today may have raised some issues that you might like further support with. Below is a list of services that may be of assistance, as may your GP:

Anxiety UK - National charity helping people with anxiety
Web: www.anxietyuk.org.uk
Tel: 03444 775 774 (Mon-Fri 9.30am to 5.30pm)
Text: 07537 416 905
Email: support@ anxietyuk.org.uk

Cruse Bereavement Care – National charity for bereaved people in England, Wales and Northern Ireland
Web: www.cruse.org.uk
Tel: 0808 808 1677

Cruse Bereavement Care Scotland – National charity for bereaved people in Scotland
Web: www.crusescotland.org.uk
Tel: 0808 802 6161

Samaritans – a talking charity for UK and ROI
Web: www.samaritans.org.uk
Tel: 116 123
Email: jo@samaritans.org
Write: Freepost RSRB-KKBY-CYJK
PO Box 9090
Stirling
FK8 2SA

If you have any questions after the focus group or would like to withdraw your data within two weeks of the attendance date, please contact me by email at: hcapp@leeds.ac.uk

Appendix 13

Interview formal email invitation

Dear

Thank you for your interest in my research. I would like to formally invite you to take part in my study.

A majority of people do not discuss death /dying until there is a medical reason to do so, and most of the conversations are held within a clinical setting. My research will be exploring people's perceptions of death/dying conversations, with the aim to consider what could be done to help facilitate open conversations about death/dying, outside of clinical settings.

Taking part in the study would involve a one-to-one interview lasting approximately 1 hour. It would occur via the web conference platform called Zoom. If you have never used Zoom, I can provide you with instructions to access it and how to use it. If you need to, we can arrange a test meeting to make sure you know how the platform works.

To take part in the study you must be over 18 years of age, be able to speak/read English (or work with a carer who does), have access to the internet/smart phone technology and provide informed consent.

Ethical approval has been given from the School of Healthcare Research Ethics Committee (SHREC project Number HREC 20-024)

I have included a copy of the information sheet, for you to keep. This form details the aims and methods of the study as well as your role. I would be grateful if you could read this information before you decide to make your decision. If you decide to participate in the research, please complete the attached consent and demographic forms and return to me as soon as possible. An electronic or typed signature will suffice.

If you require any further information regarding this study and your role, please contact me on my email and I will be happy to answer any questions you may have.

Thank you for showing an interest in my research and I look forward to hearing from you.

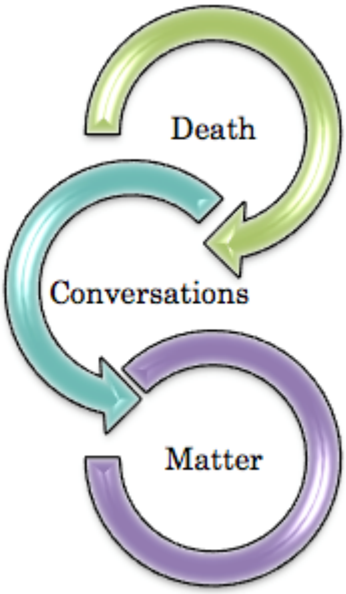
Kind regards,

Alex

Alex Pinto
hcapp@leeds.ac.uk

Appendix 14

Interview advert



My name is Alex Pinto and I am a PhD student at the University of Leeds. I am researching the conversations people have about death and dying.

The study is entirely voluntary and ethical approval has been given from the School of Healthcare Research Ethics Committee (SHREC project number: HREC 20-024)

I would like to interview individuals who have a terminal prognosis and those who do not. This will allow me to understand the different perspectives there are towards death/dying conversations.

As a thank you for taking part you will receive a £20 Amazon voucher.

If you want to find out more about this research and would consider taking part, please contact me on my email: hcapp@leeds.ac.uk

Thank you

Appendix 15

Interview participant information sheet

Participant Information Sheet

Project Title:	Exploration of lived experiences of death and dying conversations: A phenomenological study.
Researcher:	Alexandra Pinto
Supervisors:	Dr Alison Rodrigues and Dr Joanna Smith

Invitation

I would like to invite you to take part in my doctoral research study. To help you decide whether to take part in the study, I would like you to understand why this research is being done and what it would involve for you. If there is anything that is not clear, or you would like more information please contact me by email, hcapp@leeds.ac.uk. Kind Regards, Alex Pinto.

What is the purpose of the study?

The overall purpose of this study is to explore individuals' perceptions and lived experiences of the death and dying conversations. Death is an absolute reality, but conversations around death and dying are often avoided unless individuals are recently bereaved or facing a terminal prognosis.

Objectives of the study

- I will be exploring the motivations and experiences of individuals who are involved with the death positivity movement.
- I aim to understand the content and impact of death and dying conversations and events experienced and facilitated by the death positivity movement.
- I will explore if the global pandemic of COVID has influenced individual's experiences, perceptions and death and dying conversations.

Why am I being asked to take part?

The Death Positivity movement is considered a social and philosophical movement that encourages people to have open and frank discussions about death and dying. You have been contacted because you have been identified as with or without a terminal prognosis and involved with the death positivity movement. As such, your perceptions and experiences of living with/without a terminal prognosis and your interaction with the death positivity movement and how this has influenced your death/dying conversations will be invaluable.

What will happen if I decide to take part?

Please read the University of Leeds Privacy Notice for Research along with this form, and if you wish to take part, you need to return the consent form (an electronic signature will suffice) and demographic forms to me, Alex Pinto at hcapp@leeds.ac.uk. Once confirmation is received that you wish to take part, I will contact you to invite you to a one-to-one interview. Due to COVID and geographical restrictions, for your safety and convenience, the interview will be online via Zoom. You will be sent a weblink via email so that you can take part. The interview will last approximately one hour. During the interview I will be asking you a number of questions regarding your discussions of death/dying. To explore your motivations for and experiences of involvement within the death positivity movement. You do not have to share anything with me that you are not comfortable in sharing. As a participant you will be advised that the meeting will be audio and video recorded, and the confidential nature of the interview outlined. After the interview, the recording will be labelled with a number and you will be given a pseudonym (false name). Each interview will be typed up, and you will not be identifiable in the transcript.

Do I have to take part?

You do not have to take part in the study. It is entirely up to you whether you want to take part. If you decide to take part, this information sheet is for you to keep. You will also be sent via email, a consent form for you to sign. You must only sign if you agree that you understand the purpose of the study and that you wish to take part in interview and to the recording of the information collected. You will be asked to agree to me taking notes and using direct quotes from your interview in my thesis and publications. It will be ensured that you are not identified. You will also need to be in a safe, private space that will allow you to talk freely about death and dying. Before the interview starts you will be asked again if you wish to take part, and agree to video and audio recorded.

What will happen if I do not want to carry on with the study?

If you decide not to take part in the study after you have initially agreed, you can withdraw without any obligation to provide a reason. If you decide to leave the interview, you can do so without giving a reason. If you decide to leave the study after the interview has taken place, your data on transcripts will be made void. However, if you decide to leave after your interview data has been analysed, your contribution cannot be removed. If you do want to withdraw from the study, please contact me on hcapp@leeds.ac.uk.

How will my privacy be protected?

All information that is collected as part of this study will be kept strictly confidential and stored without any identifying details under secure conditions. However, if a disclosure is made that indicates that the participant or someone else is at serious risk of harm. Such disclosures may be reported to the relevant authorities.

You will be asked for permission to audio and video record the focus group. The recordings will be kept in a password protected file on the M-Drive of the University of Leeds secure server and will be destroyed once they have been transcribed. 1st Class Secretarial will also have access to the audio files for transcription purposes and have signed confidentiality agreements with the University of Leeds.

Transcripts of the focus group will be anonymised and kept as password-protected electronic files on the M-Drive of the University of Leeds secure server. Any quotes used in the dissemination of the research, will not include any identifying information. All participants will be given a pseudonym (false name). Only myself and my research supervisors will have access to the anonymised data, and they will not share this information with anyone. However, with one exception being if a disclosure is made that indicates that the participant or someone else is at serious risk of harm. Such disclosures may be reported to the relevant authorities.

What will happen following the study?

Following the interview, the recording will be transcribed and anonymised, and I will undertake various analyses. I can share the results with you. If you wish me to do this, please provide your email address following the focus group discussion. The findings will be written into a PhD Thesis and will be published in relevant health and social care journals. No participants will be identified in any publication. Transcribed data will be kept within a password-protected file on the M-Drive of the University of Leeds secure server until the point of publication. After this, the data will be destroyed. Data generated during the research will be retained in accordance with the University's Data Protection Policy.

What are the possible benefits and risks of taking part in this study?
If you decide to take part, we hope it will be enjoyable. Your contribution is valuable. There are no anticipated or known risks. Everything you share as part of your participation is voluntary, and if at any point you feel you would prefer to stop, or would prefer not to share something, that is fine. You are free to decline to answer any question that makes you feel uncomfortable. In the interview, you might want to talk about your experiences with individuals, friends or relatives at the end-of-life. While some people find it helpful to talk about their experiences to researchers this is not the same as counselling. However, I can provide you with a list of how to get further support/counselling support if you want. It is highly unlikely you will suffer harm by taking part.

Who has reviewed the study?
Ethical approval has been given from the School of Healthcare Research Ethics Committee (SHREC project Number HREC 20-024). The University adheres to its responsibility to promote and support the highest standards in all aspects of research. If you wish to make a complaint about any aspect of the study, please contact Ms. Clare Skinner, Head of Research Integrity and Governance, Secretariat, University of Leeds via email: c.e.skinner@leeds.ac.uk

Who is organising and funding the study?
This study is being undertaken as part of a PhD (Doctoral) programme of study at the University of Leeds.

Who can I contact for further information?
Hopefully, this information sheet has told you what you need to know before deciding whether to take part. If you have any queries about this study, please contact the researcher, Alex Pinto (hcapp@leeds.ac.uk) or my supervisors Dr Alison Rodriguez (a.m.rodriguez@leeds.ac.uk) and Dr Joanna Smith (j.e.smith1@leeds.ac.uk) from the University of Leeds.

Thank you for considering to take part in this study.

Appendix 16

Interview consent form

Consent to take part in the Exploration of lived experiences of death and dying conversations: A phenomenological study.	Add your initials next to the statement if you agree
I confirm that I have read and understand the information sheet V2.1 18 August 2021 explaining the above research project and I have had the opportunity to ask questions about the project.	
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. In addition, I understand that if I wish to remove any of my data following the interview, I can do so within 2 weeks of the interview date. (Please contact Alex Pinto via email: hcapp@leeds.ac.uk	
I understand that the interview will be audio and visually recorded.	
I understand that members of the research team may have access to my responses. I understand that my interview recording will be accessed by a third party (1st Class Secretarial) for transcription purposes only. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.	
I understand that the data collected from me may be stored and used in relevant future research in an anonymised form.	
I understand that relevant sections of the data collected during the study, may be looked at by individuals from the University of Leeds or from regulatory authorities where it is relevant to my taking part in this research.	
I understand that confidentiality cannot be maintained if issues suggesting unsafe practice, negligence or criminality are raised.	
I agree to take part in the above research project and will inform the lead researcher should my contact details change.	
I would like to be informed of the study results.	

Name of participant	
Participant’s signature	
Date	
Name of lead researcher	Alexandra Pinto
Signature	
Date	

Appendix 17

Interview debrief

Working Title: Exploration of lived experiences of death and dying conversations: A phenomenological study

Name of Investigator: Alexandra Pinto

Thank you very much for taking part in this study. I appreciated your time and interest.

Participating in this interview today may have raised some issues that you might like further support with. Below is a list of services that may be of assistance, as may your GP:

Anxiety UK - National charity helping people with anxiety
Web: www.anxietyuk.org.uk
Tel: 03444 775 774 (Mon-Fri 9.30am to 5.30pm)
Text: 07537 416 905
Email: support@ anxietyuk.org.uk

Cruse Bereavement Care – National charity for bereaved people in England, Wales and Northern Ireland
Web: www.cruse.org.uk
Tel: 0808 808 1677

Cruse Bereavement Care Scotland – National charity for bereaved people in Scotland
Web: www.crusescotland.org.uk
Tel: 0808 802 6161

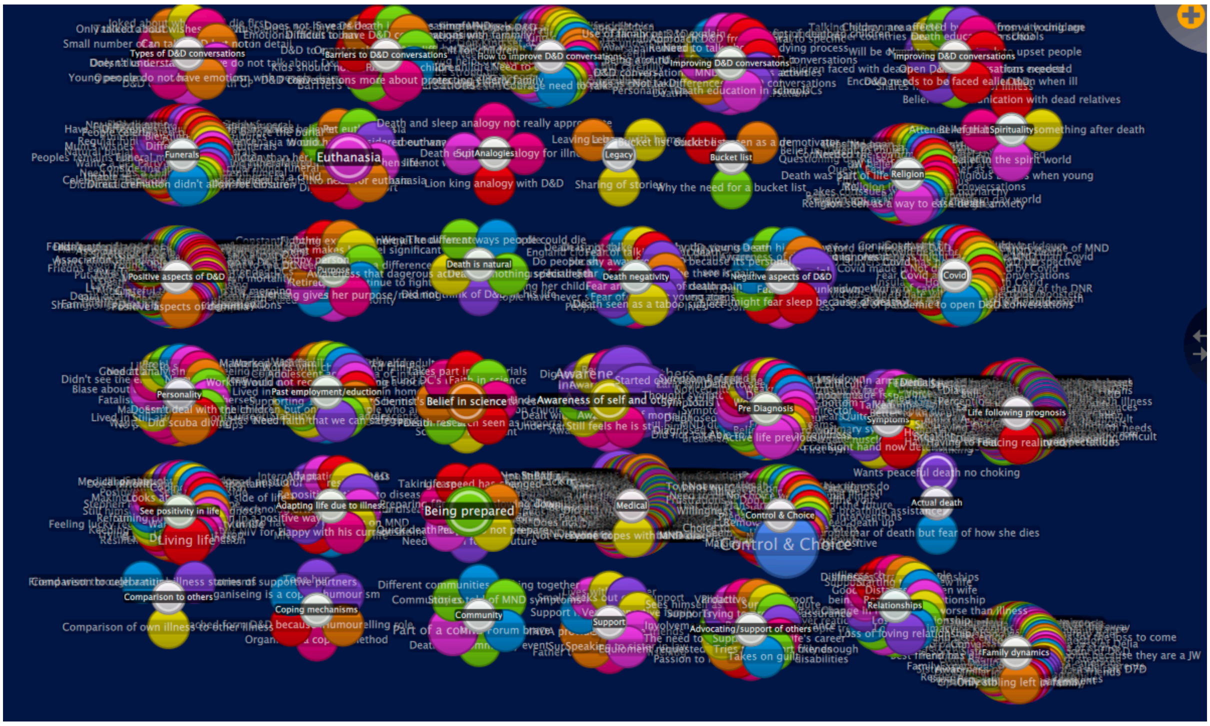
Samaritans – a talking charity for UK and ROI
Web: www.samaritans.org.uk
Tel: 116 123
Email: jo@samaritans.org
Write: Freepost RSRB-KKBY-CYJK
PO Box 9090
Stirling
FK8 2SA

If you have any questions after the interview or would like to withdraw your data at a later date, please contact me by email at: hcapp@leeds.ac.uk

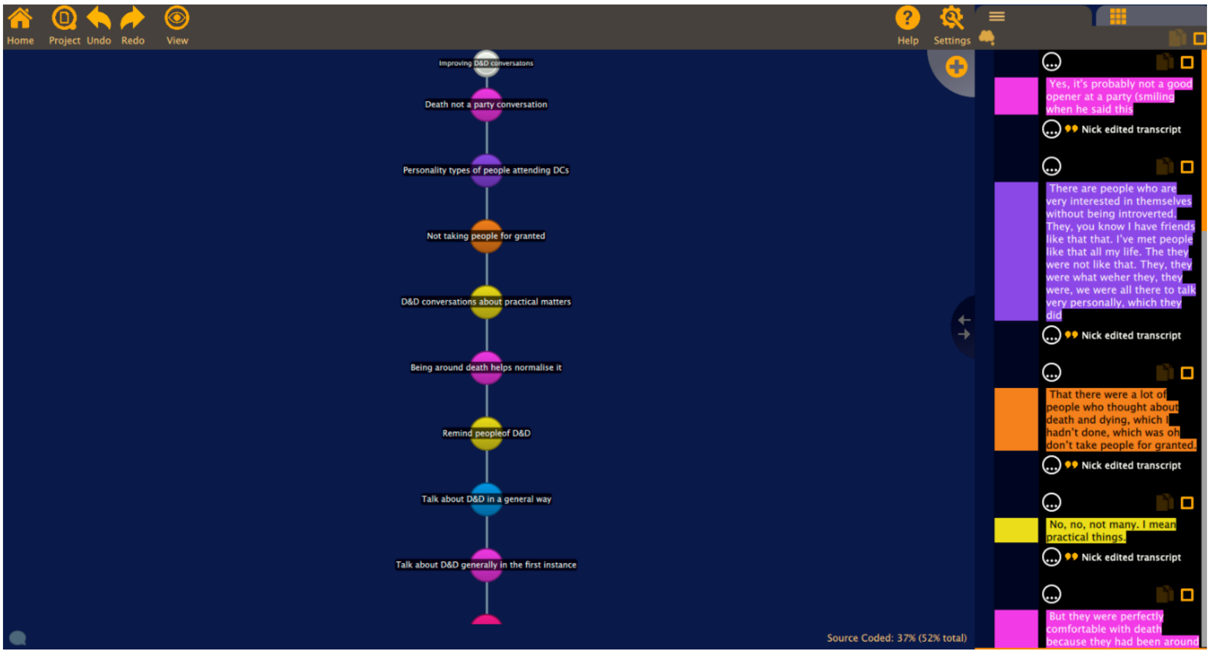
Appendix 18

Quirkos output examples

Overall picture of the output of all participants within the terminal group



Output of one of the themes



Source Coded: 37% (52% total)

Yes, it's probably not a good opener at a party (smiling when he said this

Nick edited transcript

There are people who are very interested in themselves without being introverted. They, you know I have friends like that that. I've met people like that all my life. The they were not like that. They, they were what weher they, they were, we were all there to talk very personally, which they did

Nick edited transcript

That there were a lot of people who thought about death and dying, which I hadn't done, which was oh don't take people for granted.

Nick edited transcript

No, no, not many. I mean practical things.

Nick edited transcript

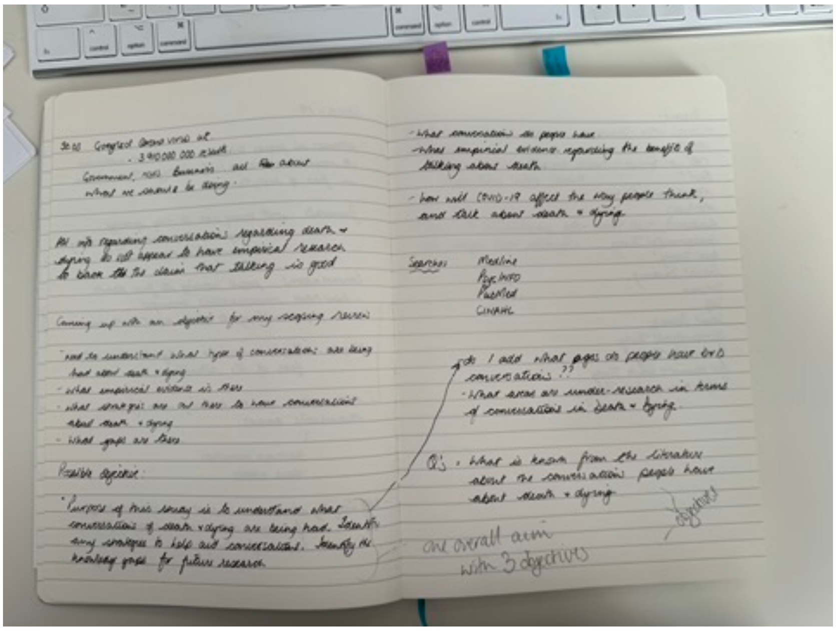
But they were perfectly comfortable with death because they had been around

This is a snapshot as all the codes could not be shown

Appendix 19

Journal extracts

Researching articles



[illegible] Googled Corona virus etc
- 3 910 000 000 results
Government, NHS, Businesses all ~~[illegible]~~ about what we should be doing.

All info regarding conversations regarding death + dying do not appear to have empirical research to back ~~the~~ the claim that talking is good

Coming up with an objective for my scoping review

- need to understand what type of conversations are being had about death + dying
- what empirical evidence is there
- what strategies are out there to have conversations about death + dying
- What gaps are there

Possible objective:

• Purpose of this study is to understand what conversations of death + dying are being had. Identify any strategies to help aid conversations. Identify the knowledge gaps for future research.

- What conversations do people have
- What empirical evidence regarding the benefits of talking about death
- how will COVID-19 affect the way people think, and talk about death + dying

Searches Medline
PsycINFO
PubMed
CINAHL

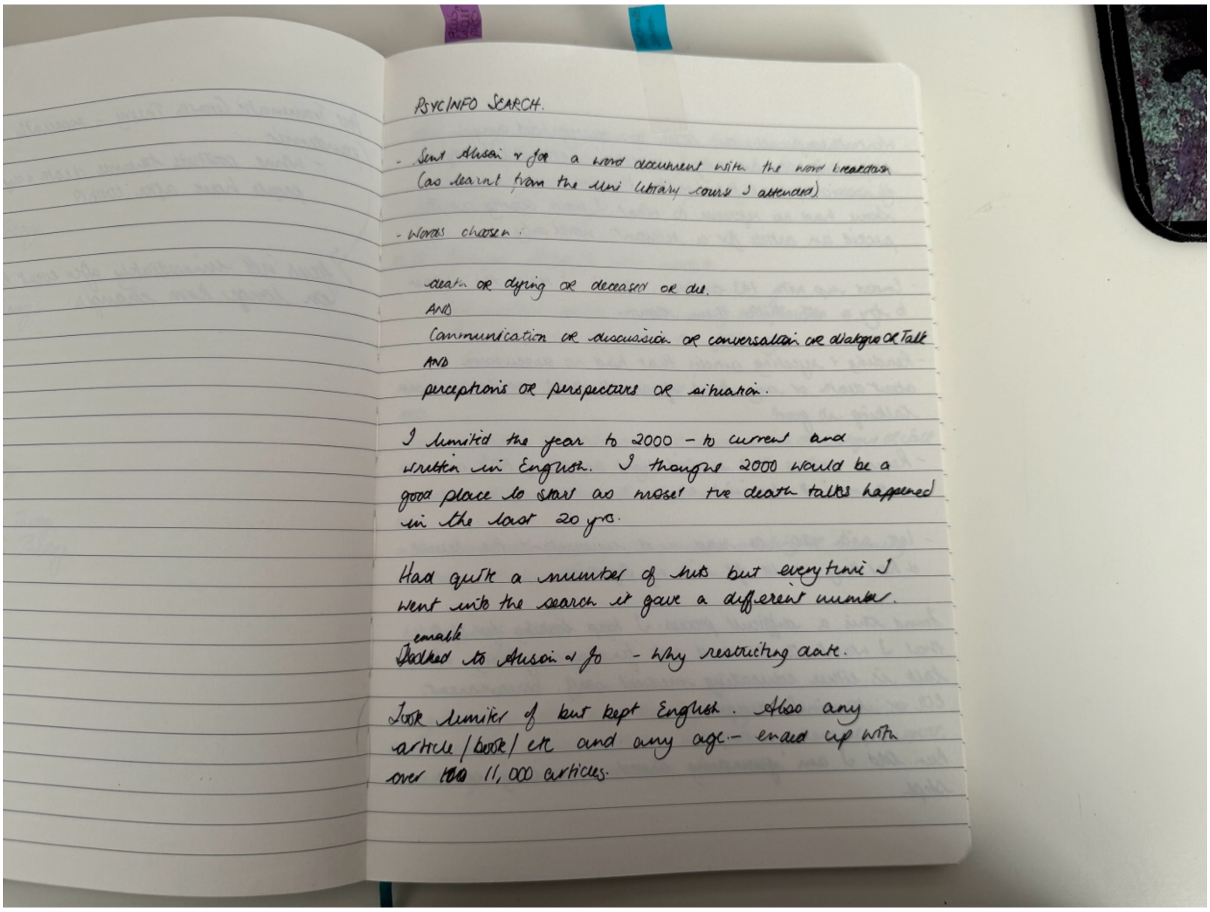
do I add what ages do people have D+D conversations ??
- What areas are under-research in terms of conversations in death + dying

Q's • What is known from the literature about the conversations people have about death + dying

one overall aim with 3 objectives

objectives

Database search



PSYCINFO SEARCH.

- Sent Alison + Jo a word document with the word breakdown (as learnt from the Uni library course I attended)

- Words chosen:

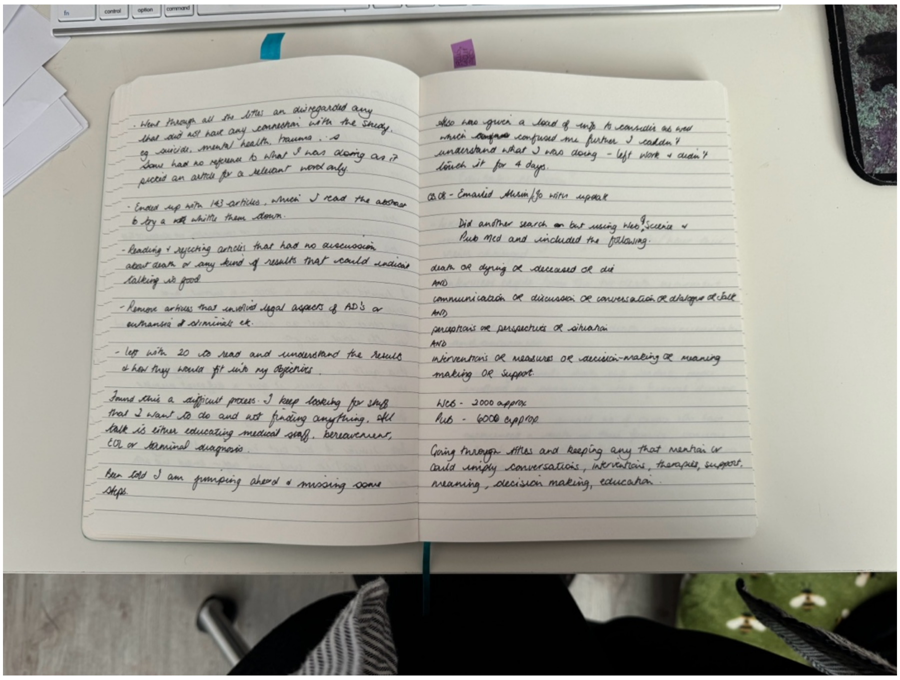
death OR dying OR deceased OR die.
AND
Communication OR discussion OR conversation OR dialogue OR Talk
AND
perceptions OR perspectives OR situation.

I limited the year to 2000 - to current and written in English. I thought 2000 would be a good place to start as most the death talks happened in the last 20 yrs.

Had quite a number of hits but every time I went into the search it gave a different number.

~~Talked~~ emailed to Alison + Jo - Why restricting date.

Took limiter off but kept English. Also any article/book/etc and any age - ended up with over ~~100~~ 11,000 articles.



- Went through all the titles an disregarded any that did not have any connection with the study. eg suicide, mental health, trauma... as some had no reference to what I was doing as it picked an article for a relevant word only.

- Ended up with 143 articles, which I read the abstract to try a ~~bit~~ whittle them down.

- Reading + rejecting articles that had no discussion about death or any kind of results that could indicate talking is good.

- Remove articles that involved legal aspects of AD's or euthanasia & criminals etc.

- Left with 20 to read and understand the results & how they would fit into my objectives.

Found this a difficult process. I keep looking for stuff that I want to do and not finding anything. All talk is either educating medical staff, bereavement, EOL or terminal diagnosis.

Been told I am jumping ahead & missing some steps.

Also was given a load of info to consider as well which ~~confuse~~ confused me further I couldn't understand what I was doing - left work + didn't touch it for 4 days.

08.08 - Emailed Alison/Jo with update

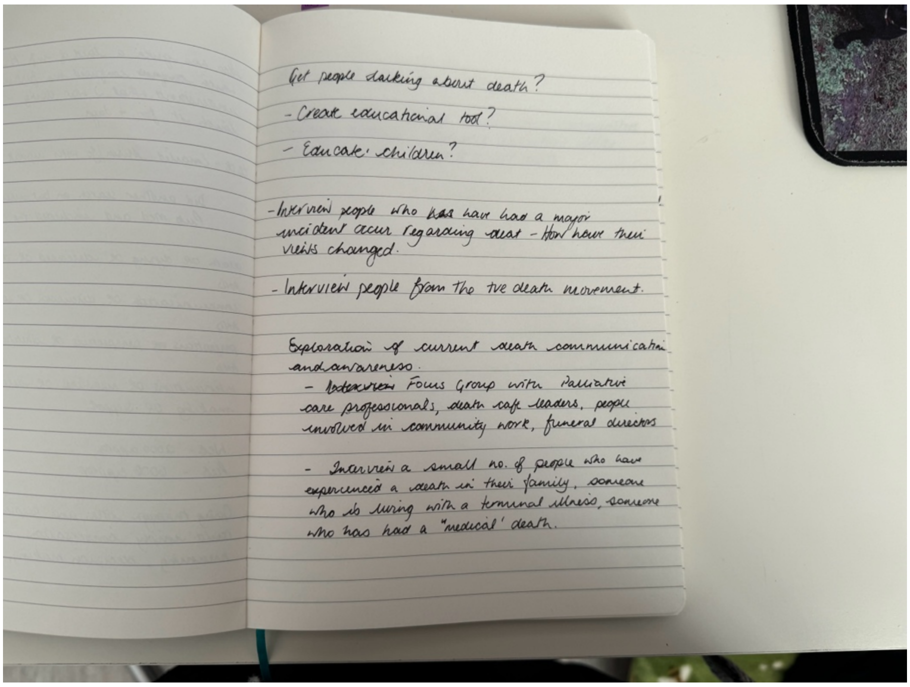
Did another search ~~on~~ but using Web of Science + Pub Med and included the following.

death OR dying OR deceased OR die
AND
communication OR discussion OR conversation OR dialogue OR talk
AND
perceptions OR perspectives OR situation
AND
interventions OR measures OR decision-making OR meaning making OR support.

Web - 2000 approx
Pub - 6000 approx

Going through titles and keeping any that mention or could imply conversations, interventions, therapies, support, meaning, decision making, education.

Thoughts on who to interview



Get people talking about death?
- Create educational tool?
- Educate children?

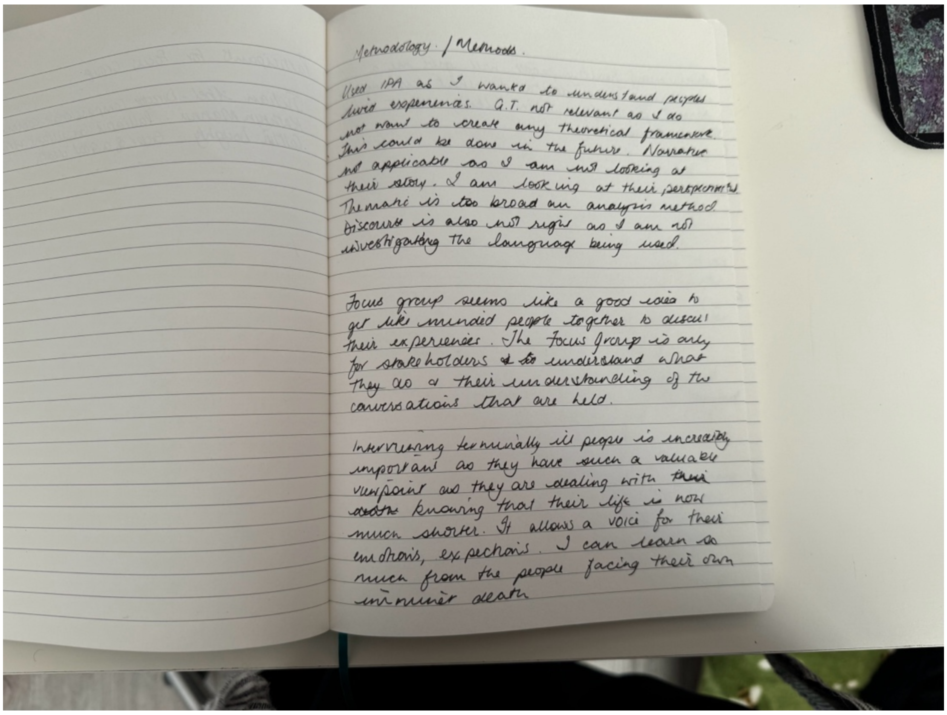
- Interview people who ~~has~~ have had a major incident occur regarding death - How have their views changed.

- Interview people from the +ve death movement.

Exploration of current death communication and awareness.
- ~~Interview~~ Focus Group with Palliative care professionals, death cafe leaders, people involved in community work, funeral directors

- Interview a small no. of people who have experienced a death in their family, someone who is living with a terminal illness, someone who has had a 'medical' death.

Methods



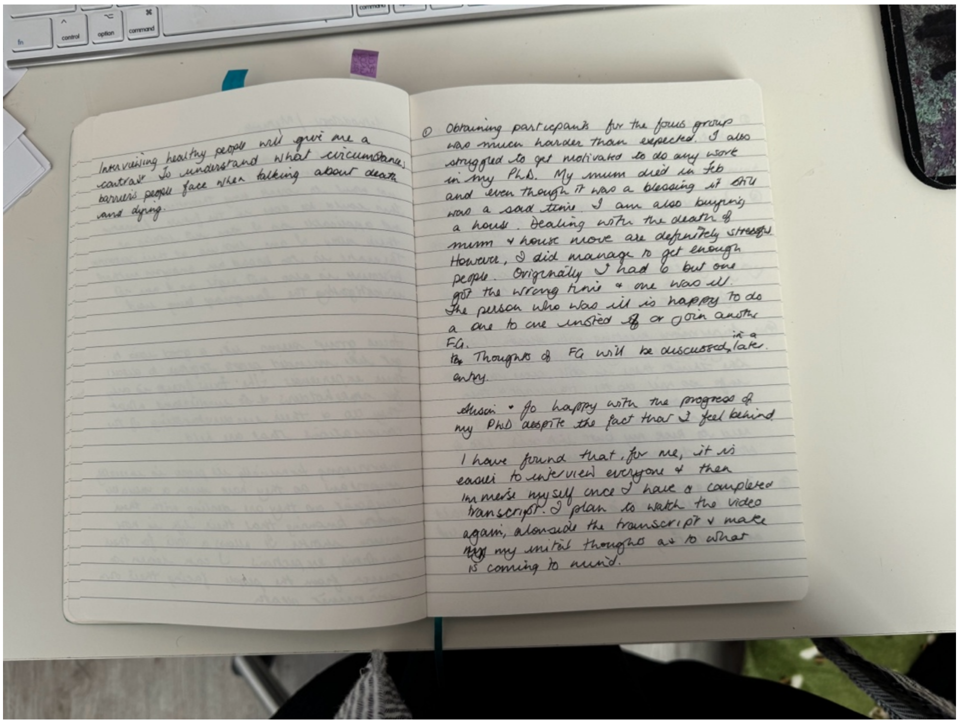
Methodology / Methods.

Used IPA as I wanted to understand peoples lived experiences. G.T. not relevant as I do not want to create any theoretical framework. This could be done in the future. Narrative not applicable as I am not looking at their story. I am looking at their perspectives. Thematic is too broad an analysis method. Discourse is also not right as I am not investigating the language being used.

Focus group seems like a good idea to get like minded people together to discuss their experiences. The Focus group is only for stakeholders ~~&~~ ~~to~~ to understand what they do & their understanding of the conversations that are held.

Interviewing terminally ill people is increasingly important as they have such a valuable viewpoint as they are dealing with ~~their~~ ~~death~~ knowing that their life is now much shorter. It allows a voice for their emotions, expectations. I can learn so much from the people facing their own imminent death

Reflection on recruitment



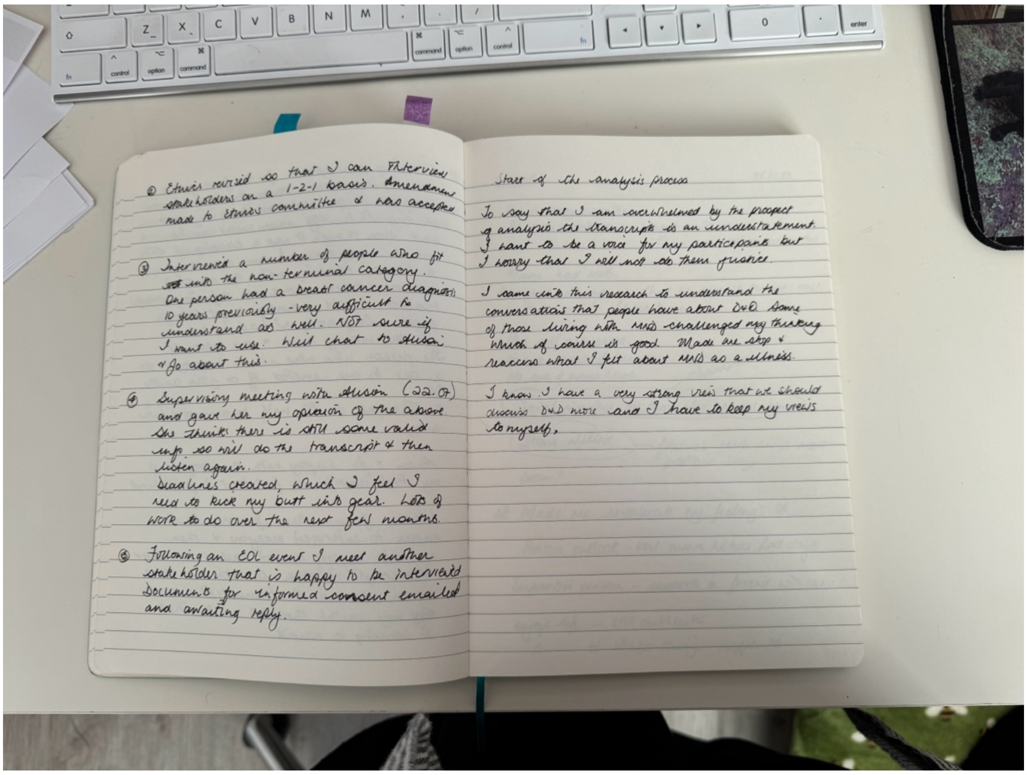
Interviewing healthy people will give me a contrast to understand what circumstances, barriers people face when talking about death and dying.

① Obtaining participants for the focus group was much harder than expected. I also struggled to get motivated to do any work in my PhD. My mum died in Feb and even though it was a blessing it still was a sad time. I am also buying a house. Dealing with the death of mum + house move are definitely stressful. However, I did manage to get enough people. Originally I had 6 but one got the wrong time + one was ill. The person who was ill is happy to do a one to one insted ~~of~~ or join another FG. ~~The~~ Thoughts of FG will be discussed in a later entry.

Alison + Jo happy with the progress of my PhD despite the fact that I feel behind.

I have found that, for me, it is easier to interview everyone + then immerse myself once I have a completed transcript. I plan to watch the video again, alongside the transcript + make ~~[illegible]~~ my initial thoughts as to what is coming to mind.

Ethics



② Ethics revised so that I can interview stakeholders on a 1-2-1 basis. Amendment made to ethics committee & was accepted

③ Interviewed a number of people who fit into the non-terminal category. One person had a breast cancer diagnosis 10 years previously - very difficult to understand as well. Not sure if I want to use. Will chat to Alison & go about this.

④ Supervisory meeting with Alison (22.07) and gave her my opinion of the above. She thinks there is still some valid info so will do the transcript & then listen again.
Deadlines created, which I feel I need to kick my butt into gear. Lots of work to do over the next few months.

⑤ Following an EOL event I meet another stakeholder that is happy to be interviewed. Documents for informed consent emailed and awaiting reply.

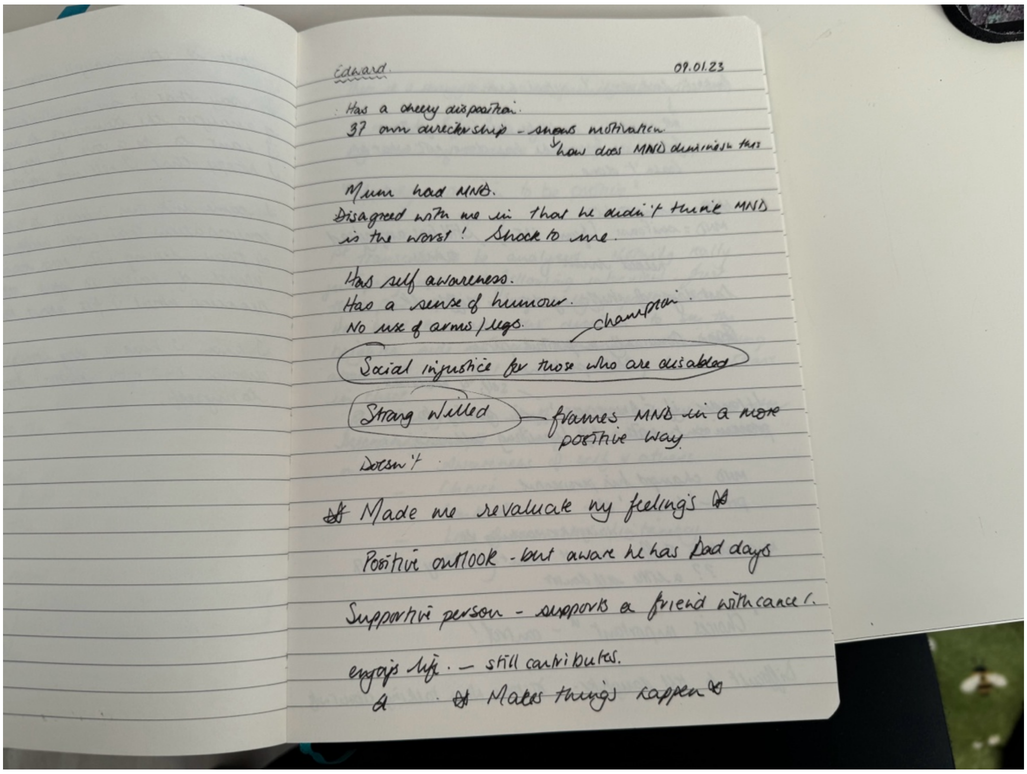
Start of the analysis process

To say that I am overwhelmed by the prospect of analysis the transcripts is an understatement. I want to be a voice for my participants but I worry that I will not do them justice.

I came into this research to understand the conversations that people have about D&D. Some of those living with MND challenged my thinking which of course is good. Made me stop & reassess what I felt about MND as a illness.

I know I have a very strong view that we should discuss D&D more and I have to keep my views to myself,

Participant - Edward



Edward. 09.01.23

Has a cheery disposition.
37 own directorship - shows motivation.
how does MND diminish this

Mum had MND.
Disagreed with me in that he didn't think MND is the worst! Shock to me.

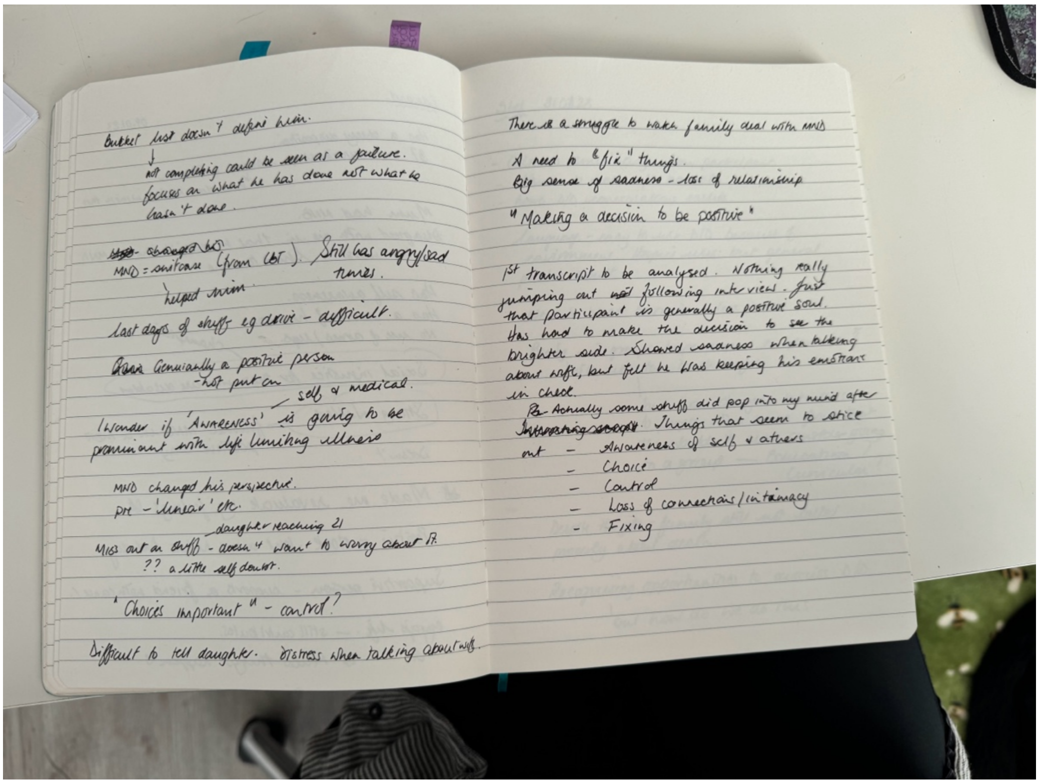
Has self awareness.
Has a sense of humour.
No use of arms/legs.
champion.
Social injustice for those who are disabled
Strong Willed — frames MND in a more positive way.
Doesn't.

Made me revaluate my feelings

Positive outlook - but aware he has bad days

Supportive person - supports a friend with cancer.

enjoys life. — still contributes.
Makes things happen



Bucket list doesn't define him.
↓
not completing could be seen as a failure.
focuses on what he has done not what he hasn't done.

~~MND~~- changed his
MND = suitcase (from CBT). Still has angry/sad times.
helped him.

Last days of stuff eg drive - difficult.

Genuinely a positive person
- not put on

I wonder if 'Awareness' is going to be prominent with life limiting illness
self & medical.

MND changed his perspective.
pre - 'linear' etc.

daughter reaching 21
Miss out on stuff - doesn't want to worry about it.
?? a little self doubt.

"Choices important" - control?

Difficult to tell daughter. Distress when talking about wife.

There is a struggle to watch family deal with MND

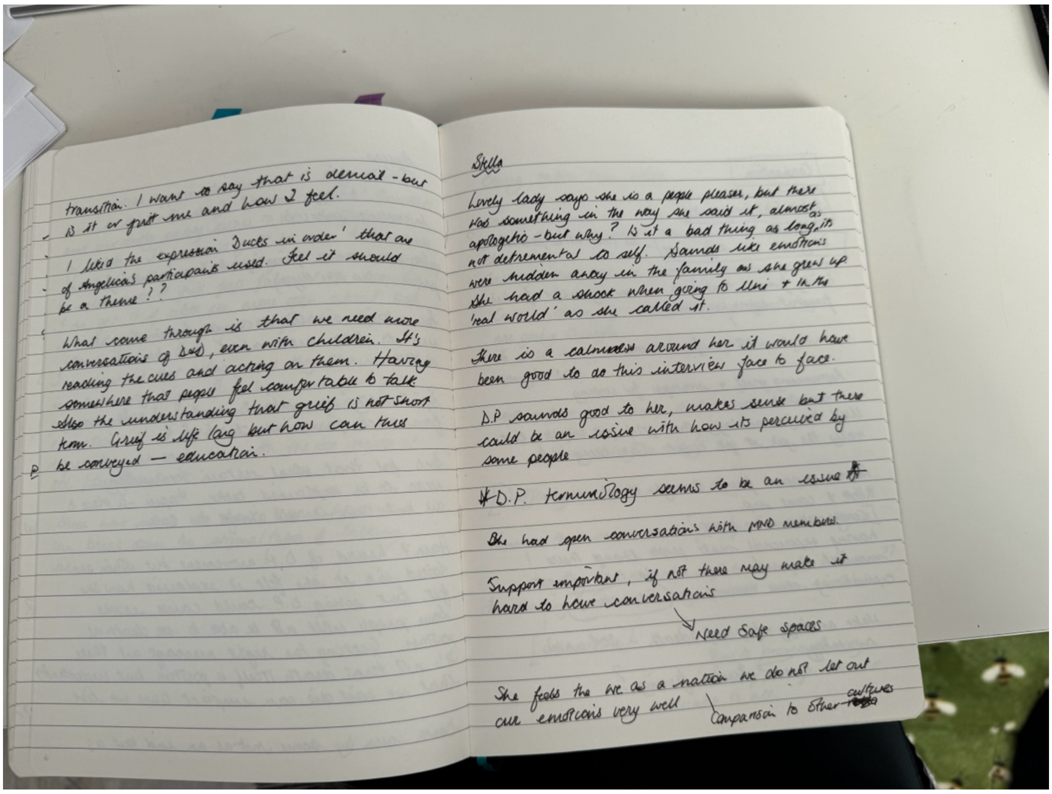
A need to "fix" things.
Big sense of sadness - loss of relationship

"Making a decision to be positive"

1st transcript to be analysed. Nothing really jumping out ~~not~~ following interview. Just that participant is generally a positive soul. Has had to make the decision to see the brighter side. Showed sadness when talking about wife, but felt he was keeping his emotions in check.

PS- Actually some stuff did pop into my mind after ~~Interesting concept~~. Things that seem to stick out
- Awareness of self & others
- Choice
- Control
- Loss of connections/intimacy
- Fixing

Participant – Stella



transition. I want to say that is denial - but is it or just me and how I feel.

I liked the expression 'ducks in order' that one of Angelica's participants used. Feel it should be a theme??

What came through is that we need more conversations of D&D, even with children. It's reading the cues and acting on them. Having somewhere that people feel comfortable to talk. Also the understanding that grief is not short term. Grief is life long but how can this be conveyed — education.

Stella

Lovely lady says she is a people pleaser, but there was something in the way she said it, almost as apologetic - but why? Is it a bad thing as long as its not detremental to self. Sounds like emotions were hidden away in the family as she grew up. She had a shock when going to Uni + in the 'real world' as she called it.

There is a calmness around her it would have been good to do this interview face to face.

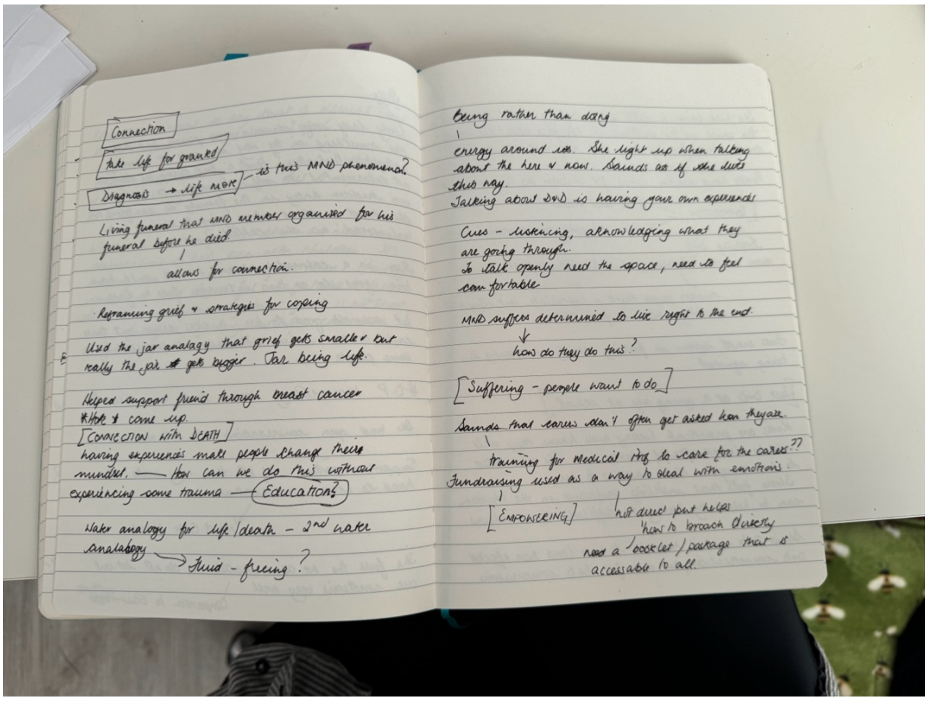
D.P sounds good to her, makes sense but there could be an issue with how its perceived by some people

\# D.P. terminology seems to be an issue \#

She had open conversations with MND members.

Support important, if not there may make it hard to have conversations
↘ Need safe spaces

She feels the we as a nation we do not let out our emotions very well
\ Comparison to other cultures



Connection

take life for granted

Diagnosis → life more — is this MND phenomenon?

Living funeral that MND member organised for his
funeral before he died.
allows for connection.

Reframing grief + strategies for coping

Used the jar analagy that grief gets smaller but
really the jar gets bigger. Jar being life.

Helped support friend through breast cancer
Hope & come up.
[CONNECTION with DEATH]
having experiences make people change their
mindset. — How can we do this without
experiencing some trauma — Education?

Water analogy for life/death – 2nd water
analalogy → fluid - freeing?

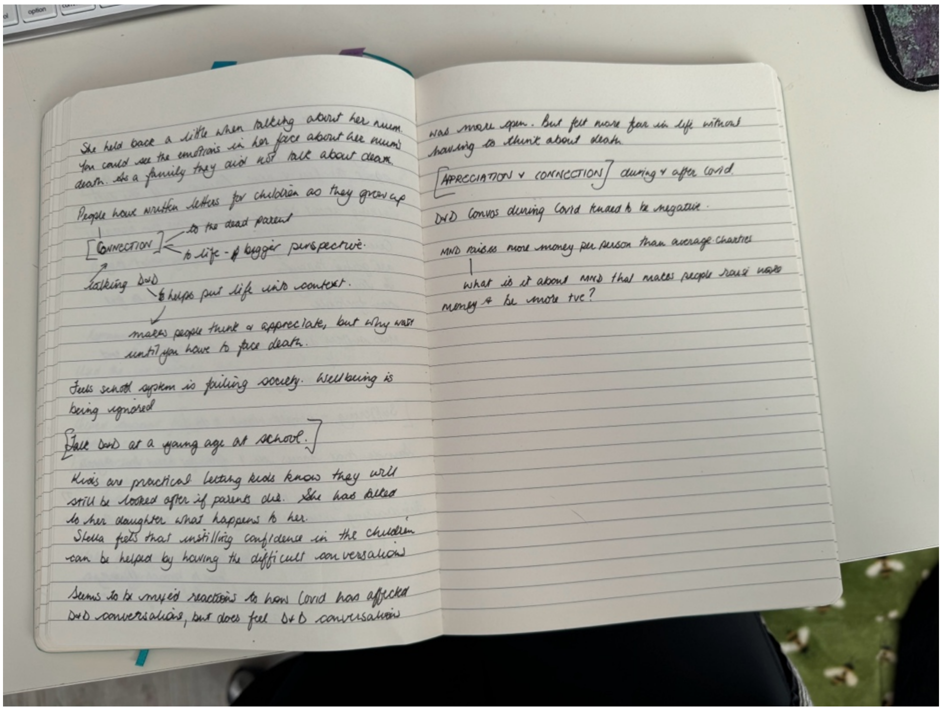
Being rather than doing
energy around us. She light up when talking
about the here + now. Sounds as if she lives
this way.
Talking about D+D is having your own experiences

Cues – listening, aknowledging what they
are going through.
To talk openly need the space, need to feel
comfortable

MND suffers determined to live right to the end.
↓
how do they do this?

[Suffering – people want to do]

Sounds that carers don't often get asked how they are.
training for medical prof to care for the carers??
Fundraising used as a way to deal with emotions.
[EMPOWERING] not direct but helps
how to broach directly
need a booklet / package that is
accessable to all.



She held back a little when talking about her mum.
You could see the emotions in her face about her mum's
death. As a family they did not talk about death.

People have written letters for children as they grow up
[CONNECTION] ← to the dead parent
← to life - bigger perspective.
talking D+D
helps put life into context.
makes people think + appreciate, but why wait
until you have to face death.

Feels school system is failing society. Wellbeing is
being ignored

[Talk D+D at a young age at school.]

Kids are practical letting kids know they will
still be looked after if parents die. She has talked
to her daughter what happens to her.
Stella feels that instilling confidence in the children
can be helped by having the difficult conversations

Seems to be mixed reactions to how Covid has affected
D+D conversations, but does feel D+D conversations
was more open. But felt more fear in life without
having to think about death.

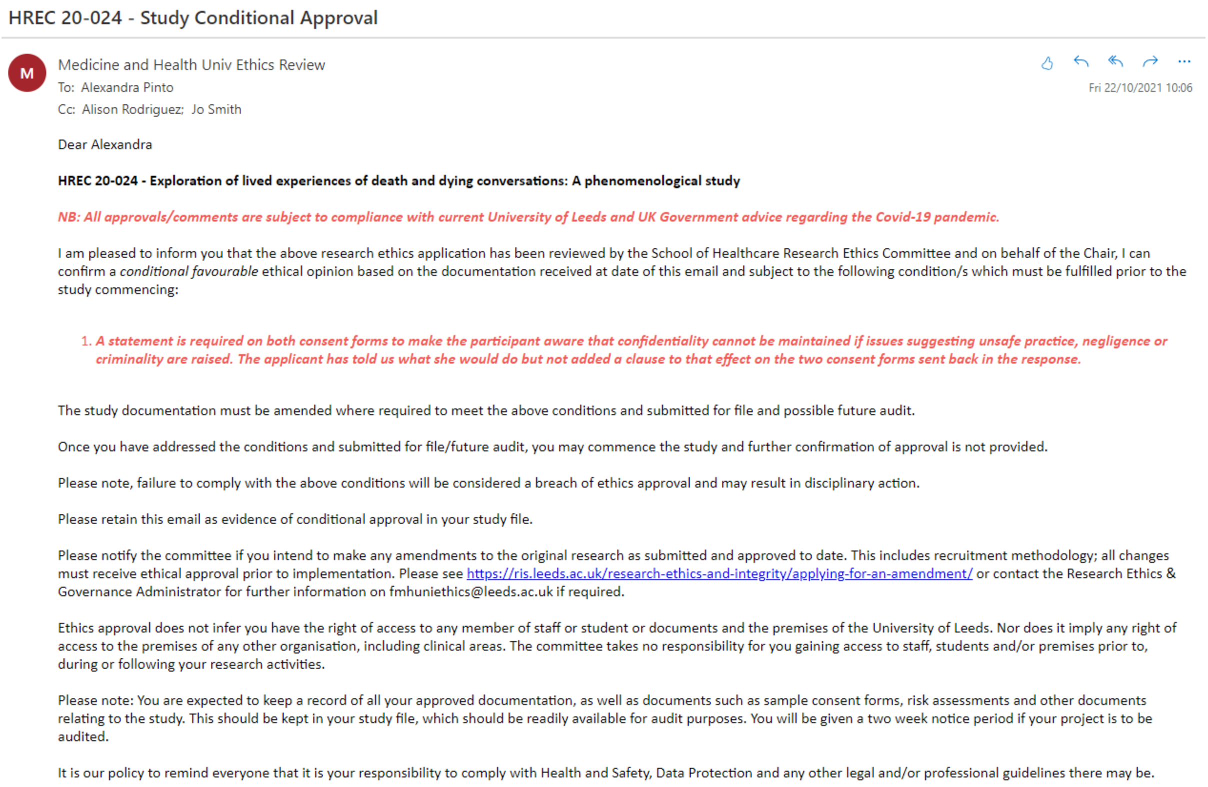
[APPRECIATION + CONNECTION] during + after Covid.

D+D Convos during Covid tended to be negative.

MND raises more money per person than average charities
what is it about MND that makes people raise more
money + be more +ve?

Appendix 20

SHREC approval of ethics



HREC 20-024 - Study Conditional Approval

Medicine and Health Univ Ethics Review
To: Alexandra Pinto
Cc: Alison Rodriguez; Jo Smith

Fri 22/10/2021 10:06

Dear Alexandra

HREC 20-024 - Exploration of lived experiences of death and dying conversations: A phenomenological study

NB: All approvals/comments are subject to compliance with current University of Leeds and UK Government advice regarding the Covid-19 pandemic.

I am pleased to inform you that the above research ethics application has been reviewed by the School of Healthcare Research Ethics Committee and on behalf of the Chair, I can confirm a *conditional favourable* ethical opinion based on the documentation received at date of this email and subject to the following condition/s which must be fulfilled prior to the study commencing:

1. ***A statement is required on both consent forms to make the participant aware that confidentiality cannot be maintained if issues suggesting unsafe practice, negligence or criminality are raised. The applicant has told us what she would do but not added a clause to that effect on the two consent forms sent back in the response.***

The study documentation must be amended where required to meet the above conditions and submitted for file and possible future audit.

Once you have addressed the conditions and submitted for file/future audit, you may commence the study and further confirmation of approval is not provided.

Please note, failure to comply with the above conditions will be considered a breach of ethics approval and may result in disciplinary action.

Please retain this email as evidence of conditional approval in your study file.

Please notify the committee if you intend to make any amendments to the original research as submitted and approved to date. This includes recruitment methodology; all changes must receive ethical approval prior to implementation. Please see https://ris.leeds.ac.uk/research-ethics-and-integrity/applying-for-an-amendment/ or contact the Research Ethics & Governance Administrator for further information on fmhuniethics@leeds.ac.uk if required.

Ethics approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds. Nor does it imply any right of access to the premises of any other organisation, including clinical areas. The committee takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

Please note: You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, risk assessments and other documents relating to the study. This should be kept in your study file, which should be readily available for audit purposes. You will be given a two week notice period if your project is to be audited.

It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

Appendix 21

SHEER meeting minutes

School of Healthcare Experts by Experience in Education & Research (SHEEER) Group
Meeting
Thursday 24th June 2021, 10.00-11.00pm
Minutes

1. Welcome & apologies

Attending: Alison Malecki-Ketchell (SHEER Chair), Elizabeth Cleave (Programme Lead Adult Nursing), Elizabeth Lavender (Academic), Janet Hirst (Head of School), Alexandra Pinto (PHD Student), Kausar Iqbal (Expert by Experience), Linda Eckersley (Expert by Experience), David Woodcock (Expert by Experience), Joseph Blunt (SES Support)

Apologies: Elaine Whitton, Jimmy Choo, Sue Taplin, Penny Roberts, David Proudlove, Gulzeab Ahmed (unable to attend due to technical difficulties)

Welcomes: Janet Hirst and Alexandra Pinto were welcomed to the meeting.

2. Minutes from SHEEER Group meeting held on 22nd April 2021

The minutes were accepted as accurate.

3. Matters Arising

Nothing to report.

4. Meet the Head of School – Professor Janet Hirst

Janet addressed the meeting and expressed her appreciation for the role that Experts by Experience play in teaching and research.

5. A phenomenological exploration of the end-of-life and death communication experiences of individuals with life limiting conditions - Alexandra Pinto

Alexandra explained the nature of her research to the meeting. The meeting provided constructive feedback on the documentation that Alexandra had prepared, as well as her plans for recruitment and the safety measures that she would have in place when conducting interviews.

6. Developing & expanding the SHEER community

Alison reported that she has been in discussion with several individuals form multiple fields and with a variety of experiences who may wish to join the SHEER community in the near future.

7. Strategy & Vision discussion

Alison invited the meeting to discuss the Strategy and Vision document that she has created. Elizabeth Lavender felt that the full document should be maintained but was too large and suggested that it might be advisable to create a summarised version which would be less intimidating for people new to the Experts by Experience community. The meeting agreed that a shorter version of the Strategy & Vision would be beneficial, especially for Experts by Experience who are thinking of joining or are new to the community. It was also agreed that the more comprehensive document which mirrors the UK Standards for Public Involvement should be created. Alison will allow Experts by Experience and members of staff a week to offer suggestions on potential improvements to the document before resending it to the community.

8. Current PPI in educational activity

Alison thanked Kausar and Mehnaz Khan for their work with the Midwifery validation. Alison also stated that the current processes of academics contacting her if they wish to engage Experts by Experience seems to be working well and is resulting in greater involvement.

9. Reflection upon practice and further development (Standing agenda item)

Any activity to report

10. Any other business

Kausar Iqbal requested that the Experts by Experience community be notified when staff leave the University so that they have the opportunity to express their thanks and say goodbye. Alison agreed that this should be passed on in future.
Kausar also queried if there were any plans for the University to reopen in the near future. Alison informed the meeting that there is currently no clarity on when campus will be fully reopened but that the Experts by Experience will be notified when a plan is in place.

11. Next meeting - Thursday 12th August 10-11 Online Teams Meeting

Appendix 22

Distress protocol

A risk management plan for dealing with any potential risk/harm to the participant has been articulated in a distress protocol

Distress protocol

This distress protocol has been adapted from work by Draucker at al., and is designed to:

- *Monitor participants' experience of distress, and*
- *Guide the researcher's response to this distress.*

Due to the nature of this research, it is anticipated that the research may elicit some psychological discomfort. The researcher will be aware of, and alert for indications of a high level of stress or emotional distress OR the exhibiting of behaviours suggestive that the interview is too stressful. Such behaviours include:

- *uncontrolled crying,*
- *incoherent speech,*
- *indications of flashbacks etc.*

If distress is detected, the interviewer will:

- *Stop the interview*
- *Offer support and allow the participant time*
- *Determine if the person is experiencing acute emotional distress beyond what would be normally expected in an interview about a sensitive topic.*
- *If detected, stop the interview completely.*

If distress reflective of what may be expected in an interview about a sensitive topic is evident, support and the following opportunities will be offered:

- *Stop the interview completely, OR*
- *Stop and regroup and then make decision to stop, OR*
- *Stop, regroup and continue.*

If distress of any level detected, at either stop point (as above) or end of interview (if continued), the interviewer will take the following actions:

- *Encourage participant to contact their regular health provider (GP or consultant for example) for follow up.*
- *Provide the participant with details of local support groups and services they may wish to access.*
- *Indicate that, with permission, the researcher will contact the participant the following day to see if they are okay.*

Should severe or acute emotional distress be detected, either during or following the interview, the researcher will:

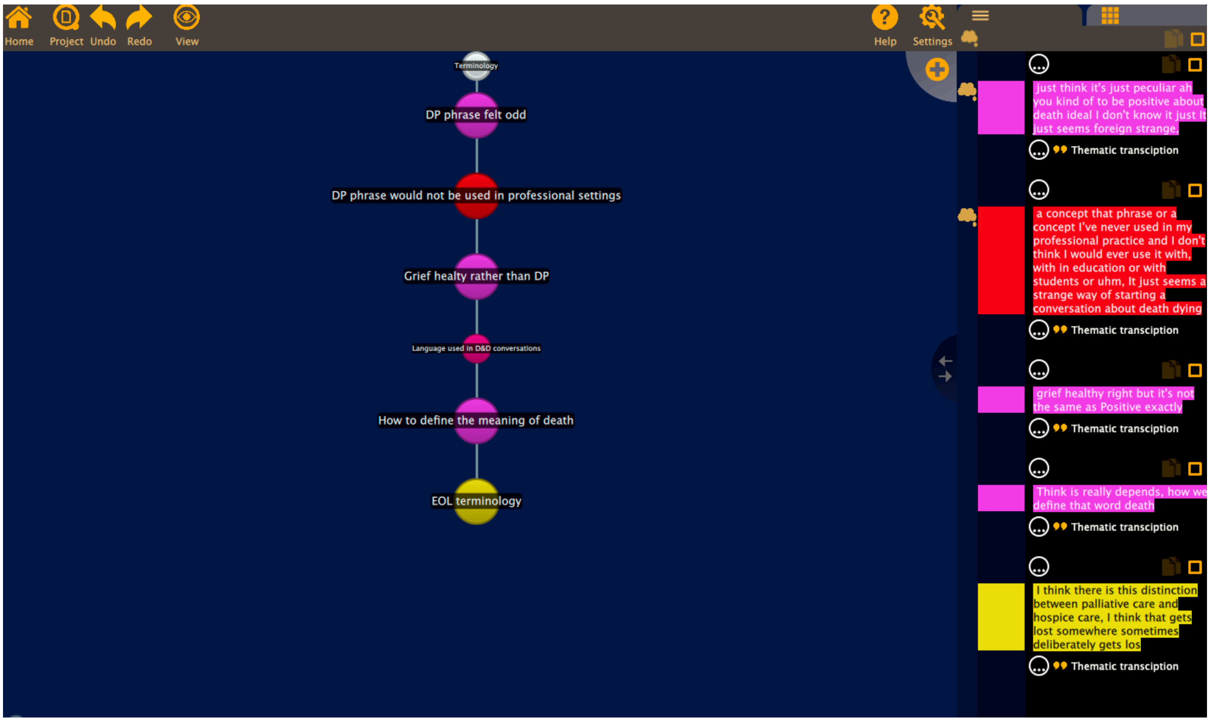
- *Request permission from the participant to contact a family member to request emotional support. OR*
- *If there are any concerns about their immediate safety dial 999 for assistance.*

Draucker, CB, Martsolf, DS, and Poole, C. (2009) Developing distress protocols for research on sensitive topics. Arch Psychiatr Nurs; 23(5):343-350.

Appendix 22

An example of theme development: Stakeholders Group

I started the coding process via a software program called Quirkos. In this system, I was able to add each transcript and code individually. The following is a screen print of one of the potential themes with the codes attached:



just think it's just peculiar ah you kind of to be positive about death ideal I don't know it just It just seems foreign strange,

Thematic transciption

a concept that phrase or a concept I've never used in my professional practice and I don't think I would ever use it with, with in education or with students or uhm, It just seems a strange way of starting a conversation about death dying

Thematic transciption

grief healthy right but it's not the same as Positive exactly

Thematic transciption

Think is really depends, how we define that word death

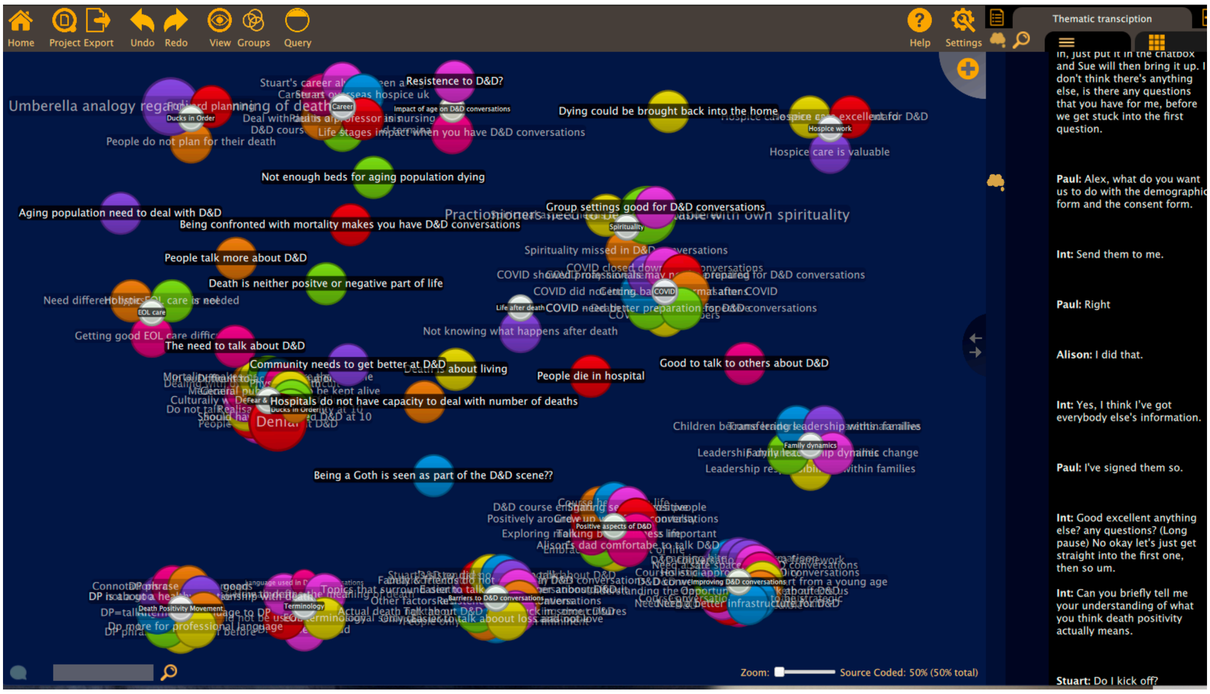
Thematic transciption

I think there is this distinction between palliative care and hospice care, I think that gets lost somewhere sometimes deliberately gets los

Thematic transciption

Each of these quirks (bubbles) that you see on the screen is the individual code which is attached to the relevant section of the transcript. This can be seen on the right-hand side of the image.

As I pulled the codes together and created the themes the screen looked more as follows:



in, just put it in the chatbox and Sue will then bring it up. I don't think there's anything else, is there any questions that you have for me, before we get stuck into the first question.

Paul: Alex, what do you want us to do with the demographic form and the consent form.

Int: Send them to me.

Paul: Right

Alison: I did that.

Int: Yes, I think I've got everybody else's information.

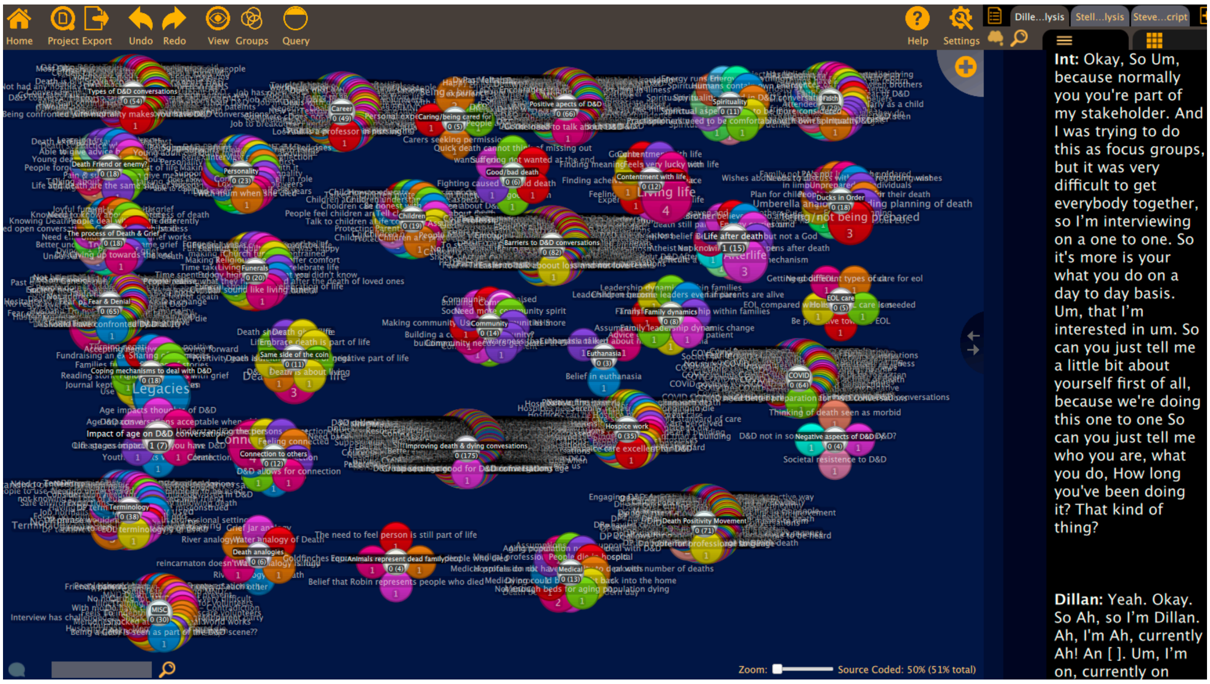
Paul: I've signed them so.

Int: Good excellent anything else? any questions? (Long pause) No okay let's just get straight into the first one, then so um.

Int: Can you briefly tell me your understanding of what you think death positivity actually means.

Stuart: Do I kick off?

All the themes were created in white colour to show that this was a theme. As I went through all the codes, I would add to what was felt the correct theme or a new theme was created. I repeated this process with all the stakeholders' interviews and brought them together in one Quirkos file:



Int: Okay, So Um, because normally you you're part of my stakeholder. And I was trying to do this as focus groups, but it was very difficult to get everybody together, so I'm interviewing on a one to one. So it's more is your what you do on a day to day basis. Um, that I'm interested in um. So can you just tell me a little bit about yourself first of all, because we're doing this one to one So can you just tell me who you are, what you do, How long you've been doing it? That kind of thing?

Dillan: Yeah. Okay. So Ah, so I'm Dillan. Ah, I'm Ah, currently Ah! An [ ]. Um, I'm on, currently on

This system allows all the coding, transcripts and memos to be on file.

These are some ideas that I had whilst coding and working through the codes when grouping them into themes.

- Death acceptance is similar to opening and shutting imagery and how death appears and disappears in lifeworlds.
- Expectedness and none expectedness, the daily interruption of it or not, how it is pushed back or embraced
- The temporality of death acceptance – age, proximity to death, impact of experience on outlooks
- Spiritual connectivity
- Awareness of the variance in being toward death in introducing death concepts, awareness of different life experiences, related holistic development and cultural beliefs impact on being toward death/talking about death and related openness
- Age, life experiences, spiritual belief systems and believed proximity to death can impact on perceptions of death and dying and upon acceptance and fear (Atheist in a foxhole metaphor).
- Affording spatiality for death talk (space in the phenomenological sense – space in time, space in life, space in the mind…)
- Meaning making through death talk - What we say and how we say it matters
- The positive dynamics of sharing - Self reflections and coping, generational openness and increased acceptance of the life stage through education
- acknowledgement of cultural norms and shifts, historical and current taboos, and how different personhoods can be impacted by context can influence the fluidity of death and dying conversations, the stance an individual will make/ take towards them, and their related level of openness. A professional may allow death to enter their professional life as a leader or conversation facilitator. Still, their response and feelings towards that phenomenon if occurring in their home worlds might differ, and their positioning on the matter may take a different turn – we all have different levels of openness, vulnerability and being toward death in different contexts.

At this point, I transferred the theme names to post-it notes and placed them on a Pin-board so that I could view them, see if there were overlaps, revise the theme names, amalgamate themes and decide how to present them. This can be seen in the snap shot of the creation of Theme 1 in the following table:

Theme 1	Sub themes	Quirkos themes
Differing perspectives on death and dying	Individual, societal & cultural constructs of death & dying	Negative aspects of death and dying, Fear and denial, Spirituality, Faith, Animals representing dead family, Death analogies, Life after death

	Spiritual and religious influences on experiences and perceptions	Negative aspects of death and dying, Fear and denial, Spirituality, Faith, Animals representing dead family, Death analogies, Life after death,
	Death as an inevitability – preparing & planning	Ducks in order, Same side of the coin, Death friend or enemy, Euthanasia, EOL care, Good/bad death, Medical, Hospice
	The experience of post-death rituals and their impact on death and remembrance	Contentment with life, Funerals, Hospice, The processes of death & grief,
	Death in a positive light	Death positivity movement, Positive aspects of death and dying, Death in a positive light.

This process of Post-it notes was used for Themes 2 & 3. Once I was happy with the themes, and how they fit together, I created a set of final themes that were used in the thesis:

Theme 1: We are all part of the sea
    Sub-theme 1: Individual, societal & cultural constructs of death & dying
    Sub-theme 2: Spiritual and religious influences on experiences and perceptions
    Sub-theme 3: Death and bereavement, preparation & positivity.

Theme 2: Shifting death and dying conversations perspectives
    Sub-theme 1: Types of Death & dying Conversations
    Sub-theme 2: Barriers to death & dying conversations
    Sub-theme3: Facilitators to good death & dying conversations

Theme 3: Holding hands with death and dying
    Sub-theme 1: Community readiness
    Sub-theme 2: Family openness
    Sub-theme 3: Negotiating personal experience
This whole process was repeated with the two other groups.