‘Living Well on Borrowed Time’: An Interpretative Phenomenological Analysis of Individuals’ Experiences of Living with Terminal Cancer

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Declaration

I hereby certify that this material, which I submit for assessment on the programme of study leading to the award of Doctor of Philosophy (PhD) is entirely my own work, and that I have exercised reasonable care to ensure that the work is original, and does not to the best of my knowledge breach any law of copyright, and has not been taken from the work of others save and to the extent that such work has been cited and acknowledged within the text of my work.

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Dedication

This thesis is dedicated to my wonderful dad, Billy. Your strength, positivity and hope during your terminal cancer journey has provided inspiration for this research and my doctoral work. Thank you for your endless love and for being you.

"Did you ever know that you're my hero? And everything I would like to be? I can fly higher than an eagle, for you are the wind beneath my wings"

Bette Midler.

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List of Abbreviations

Abbreviation	Associated Word
CASP	Critical Appraisal Skills Programme
CSO	Central Statistics Office
DCU	Dublin City University
ENTREQ	Enhancing Transparency in Reporting the Synthesis of Qualitative Research
GET	Group Experiential Theme
IPA	Interpretative Phenomenological Analysis
NCCP	National Cancer Control Programme
PET	Personal Experiential Theme
PhD	Doctor of Philosophy
PhD thesis/project	Doctoral thesis/project
PPI	Public and Patient Involvement
UK	United Kingdom
USA	United States of America
WHO	World Health Organization

Abstract

Thesis Title: ‘Living Well on Borrowed Time’: An Interpretative Phenomenological Analysis of Individuals’ Experiences of Living with Terminal Cancer

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Annually, approximately 10,000 people in Ireland die due to cancer, with many following a terminal cancer (TC) diagnosis. For TC patients, the awareness of their approaching death may lead to psychosocial and spiritual distress as they come to terms with their advancing illness and move towards death. This study aimed to explore the phenomenon of living with TC.

A qualitative meta-synthesis of 37 studies was completed in phase one to examine and synthesise evidence on spirituality as experienced by TC patients. These findings highlighted how spirituality can positively impact the lives of TC patients and can be a transformative experience that provides peace at end-of-life. In phase two, ten (N=10) semi-structured interviews were conducted with TC patients to explore their lived experiences. Following interpretative phenomenological analysis, six themes were identified.

While living with TC, participants focused upon *Recovering Control in Uncertain Times*, as while they could not control their prognosis, they regained control over other aspects of their lives. As participants experienced existential angst, they were *Gaining an Increased Awareness of Time* and focused on living well and leaving a legacy. They described this experience as *Negotiating a Changing Identity* as they became a TC patient and re-defined themselves following their diagnosis. Participants reported *Finding Comfort through Connection* with themselves, God and nature. They highlighted that *Navigating the Social World* required them to detach from some relationships and to cultivate more meaningful ones with those who mattered most. Participants posited that *Journeying with Hope* was dynamic as they may have experienced feelings of hopelessness but hope helped them to live well with TC also.

These findings highlight the multi-dimensional nature of living with TC and the transformative role of spirituality in the lives of TC patients. The findings can inform future research, healthcare practice and policy in health and psycho-oncology.

Chapter One:
Introduction

"You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die"

Dame Cicely Saunders, founder of the hospice movement.

Chapter One

Introduction

1.1. Research Background

Each year, over 30,000 people die in Ireland, with approximately a third of deaths caused by cancer (Central Statistics Office, 2023; National Cancer Registry Ireland, 2022) with a large number of these following from a terminal cancer diagnosis. While terminally ill patients often face physical and emotional distress associated with their illness, they also have to cope with spiritual and existential concerns that are brought on by their terminal diagnosis (Ross & Austin, 2013). Research has shown that, following a cancer diagnosis, and where patients may be faced with the possibility of death, they may begin to reflect on their own finitude, mortality and the temporality of life, where their very existence, values and meaning in life are questioned (Knox, 2020). For terminal cancer patients, the awareness of their approaching death may lead to emotional, social and spiritual distress as patients attempt to come to terms with their advancing illness (Kyota & Kanda, 2019). According to Willig and Wirth (2018), it is important that future research is conducted to gain a better understanding of the experience of living with terminal cancer to inform future healthcare practice and policy, and to ensure that the relevant supports are provided to this population at end of life.

Lundquist (2019) suggested that a dichotomy exists between how those living with advanced cancer are perceived and how they actually feel while living with their illness. This disjunction is also reflected in the context of terminally ill patients as while literature suggests that existential distress and spiritual suffering are important aspects of care to consider at the end of life, these facets of wellbeing are poorly understood by healthcare professionals (LeMay & Wilson, 2008). The key issues identified within literature surrounding the lack of understanding of the phenomenon of living with terminal cancer are reflected in the (Irish) National Cancer Strategy 2017-2026, which has identified the need to better understand and address the psychosocial and spiritual needs of individuals at all stages of the cancer trajectory (Department of Health, 2017). Despite there being a call for psychological support at end of life within the The National Cancer Control Programme's (NCCP) model for psycho-oncology (Greally et al., 2020), they also identified a shortage of interdisciplinary healthcare supports in certain areas of Ireland as a psycho-oncology service existed in only two out of the eight national cancer centres and one of these operated in a part-time capacity at the time the report was written. These developments in modern healthcare policy in Ireland suggest that both healthcare professionals and policy makers are aware of the lack of understanding that exists between these stakeholders and patients and highlight the importance of medical and healthcare research in informing these policies moving forward. Therefore, research exploring the lived experience of those living with terminal cancer is necessary to address the lack of understanding that exists between patients and healthcare professionals within the healthcare system and to inform future healthcare policy and practice. Based on these findings and recent developments within healthcare policy, this study aims to explore the experience of living with terminal cancer from a patient's perspective.

1.2. Understanding and Defining Terminal Cancer

Within the literature examining terminal disease, there is lack of consistency on the definitions utilised within the field referring to the classification of one's disease, the stage of one's terminal disease and the type of care that they require. Cordeiro and colleagues (2020) recently highlighted that there is a lack of consensus within literature on the definition of terminal illness itself, which had led to a lack of consistency and misunderstanding among scholars in this field. Traditionally, terminal illness was characterised by the transition from receiving active treatment focusing on extending one's life in terms of time, to receiving palliative treatment and focusing on quality of life as one approached their death (McCusker, 1984). According to Calman (as cited in Saunders, 1978), for cancer to be described as 'terminal' it needs to satisfy three criteria:

1. The patient must have received a firm diagnosis of a progressive disease with symptoms related to the malignant disease and not related to other non-malignant disease or treatment,
2. All conventional cancer treatment with the aim of curing the disease (such as surgery, chemotherapy, radiation therapy etc.) has been used to the full and was deemed unsuccessful in terms of curing the disease,
3. The acknowledgement of the imminence of death.

This seminal definition and the provision of these criteria have been useful to other researchers in the area and have informed further definitions of terminal illness within existing literature. Terminal illness, according to Buntin and colleagues (2004), refers to illnesses that are progressive and incurable by nature and that will ultimately culminate in the death of patients

(Hui et al, 2014). However, tensions exist about how long one's prognosis may be with a terminal illness while some studies suggest 12 months (Proot et al., 2004), 6 months (Meghani, 2004; Rondeau & Schmidt, 2009) or as little as 3 months in some cases (Napolskikh et al., 2009). However, according to the International Association for Hospice and Palliative Care, a terminal condition may refer to both malignant and non-malignant illnesses with a poor prognosis that is seen as incurable (Hui et al., 2014).

Further, within literature, there is a lack of understanding between different terms that are used to describe the stage of an illness at which patients are at with terms such as 'actively dying' or 'end-of-life' being commonly used (Izumi et al., 2012; Hui et al., 2012). Despite these terms being used interchangeably, they do not represent the same stage of the cancer experience and need to be recognised and acknowledged as individual concepts to truly recognise and understand the needs of terminal cancer patients depending on their stage across the cancer trajectory. 'End-of-life' refers to the final stages of life where both physical and psychological symptoms of illness deteriorate and life expectancy is less than 12 months (Cordeiro et al., 2020). As patients are deemed to have a short prognosis due to the progression in their disease, it is at this point that they face increased existential distress (LeMay & Wilson, 2008). In contrast, 'actively dying' refers to the days or hours just before the death of a patient, when his or her physiological bodily functions start to deteriorate and diminish (Kintzel et al., 2009). Hence, the focus on temporality and death in these definitions highlight that they are very different stages within the experience of terminal illness.

Similar to other concepts within the wider death and dying literature, the terms used to describe the type of care required for those with a terminal illness are also inconsistent which leads to contradiction and misunderstanding within the field of research and practice. The terms ‘palliative care,’ ‘terminal care’ and ‘end of life care’ have been used interchangeably within literature but each of these terms need to be defined individually to clarify what stage of illness the patient is at, and to determine what type of support is needed for patients (Van Mechelen et al., 2013). The period of ‘terminal care’ is said to begin when one’s active treatment (that is with the aim of curing the illness) concludes and the focus shifts to symptom management until the death of the patient (Parkes, 1978). While the aims of terminal care and palliative care are similar in that they both aim to prioritise the quality of life of the patient by providing a relief from pain and psychological, spiritual and existential distress while not trying to postpone death, there are some differences that must be acknowledged (Radbruch et al., 2020).

According to the World Health Organization (WHO) (2020), palliative care aims to maintain and improve the quality of life of patients and their families who are facing physical, psychological, social and/or spiritual challenges associated with terminal illness or disease. While literature suggests that in medical practice death itself has often been considered as unnatural by healthcare professionals rather than a natural process that all will experience at one point in their lives, and as a consequence, those dying may have been in pain within hospitals (Connors et al., 1995; Rome et al., 2011). In response to this, the hospice movement and palliative care were founded and introduced focusing upon improving care standards for those who were dying (Milicevic, 2002). While palliative care has been associated with end of life as hospice care focuses on providing holistic care to the patient in their final weeks and days of life

(Currow et al., 2020), palliative care is not restricted to within a hospice setting (Muir et al., 2010; Rabow et al., 2013). Further, best practice suggests that palliative care should be introduced earlier within one’s treatment plan and is not only associated with end of life care (Radbruch et al., 2020). This proposition mirrors the more recent definition of palliative care developed by the International Association for Hospice and Palliative Care who defined it as “the active holistic care of individuals across all ages with serious health-related suffering due to severe illness and especially of those near the end of life” (Radbruch et al., 2020, p.754). The WHO (2020) highlighted that only 14% of those who require palliative care actually receive it and that it should be included early within one’s disease to maximise their wellbeing and reduce unnecessary hospital admissions. While the perception is that palliative care and terminal or end of life care are the same, this has caused uncertainty about when is the correct time to introduce palliative care within the care planning of patients with progressive diseases (Rome et al., 2011; Bakitas et al., 2020; Ryan et al., 2020). Krau (2016) highlighted that end of life care specifically refers to a sub-portion of palliative care that is focused upon caring for terminally ill patients in the last year of their lives allowing them to maintain a quality of life and to die with dignity.

By virtue of the lack of consensus and clarity within both the death and dying and the terminal illness literature on the classification of incurable illnesses and the lack of clear guidance regarding the stage of one’s illness and the care they require, this has also caused confusion within the cancer literature. Different terms such as ‘advanced cancer,’ ‘incurable cancer’ and ‘terminal cancer’ have all been used to describe cancer that cannot be cured, however, there are still some important differences to consider when using these terms (Cordeiro et al., 2020). Advanced cancer is a term that is widely used within health psychology and oncology; however, there is no clear definition available. Studies referring to their participants as having advanced cancer specify that they have lived with incurable cancer for different ranges of time ranging from 20 years at the time of participation in some cases (Killoran et al., 2002), while others state that participants have a prognosis up to approximately one year (Zimmerman et al., 2014). Further, focusing on clinicians' estimates of a patient's prognosis may be problematic as studies have shown that their estimations are poor, and that the effectiveness of prognostic tools significantly differ (Glare et al., 2003; Simmons et al., 2017). Hence, focus has shifted to providing a definition that is not dependent on the provision of a prognosis given that patients are living with advanced cancer for a prolonged period of time (Lewis et al., 2016).

Advanced cancer has been defined as "locally recurrent or metastatic, such that palliation rather than cure was [is] the goal" (Gaston & Mitchell, 2005, p.2253). Despite this definition, Haun and colleagues (2017) posited that not all advanced cancers are metastatic such as a high-grade brain tumour which may be considered as advanced but is not metastatic. Similarly, the American Cancer Society (2020) has defined advanced cancer as cancer that cannot be cured, however, advanced cancer is not necessarily considered terminal as many patients can control their disease and continue to live for a long period of time following their diagnosis. While advanced cancer may be responsive to life-prolonging treatment, this is not the case in terminal cancer. The focus of treatment for terminal cancer is symptom control and palliative care (Kim et al., 2016). Dittus and colleagues (2017) asserted that many individuals with advanced cancer may live well for several years, although they have been diagnosed with a life-limiting illness. In contrast, a scoping review conducted by Cordeiro and colleagues (2020) identified that terminal illness specifically refers to an illness that is no longer amenable to curative treatment and has a prognosis of less than 12 months. Additionally, end of life may refer to a more specific period of time that is shorter than a year but could be hours, weeks or months (Cordeiro et al., 2020; Hui et al., 2014). Hence, while both advanced and terminal cancer are deemed as incurable, the key difference between both is the temporal aspect of the disease. To address the lack of clarity surrounding the distinction between these terms, an operational definition of terminal cancer has been developed by the researcher. In this study, terminal cancer exclusively relates to the final phase of one's advanced cancer whereby they have a prognosis of less than twelve months.

The population that has been identified as the most appropriate to focus upon in this study to truly understand the phenomenon of living with terminal cancer is those living with cancer that has been deemed as 'terminal' based on the definitions above (i.e., living with incurable cancer and a prognosis of less than twelve months). This decision was made as those living with advanced cancer are not always acutely aware of their prognosis and may not consider themselves as having entered the 'end of life' phase yet. In contrast, those living with terminal cancer have been advised that their treatment is no longer curative in nature and that their prognosis indicates that they have entered the 'end of life' phase in their care plan. Hence, this specific patient population has been identified as appropriate participants for this study as a terminal cancer diagnosis has been widely documented to have the potential to trigger psychological (Götze et al., 2014; Liao et al., 2018), social (Warth et al., 2020), spiritual (Wang et al., 2017) and existential concerns for patients (Maiko et al., 2019) as they move closer towards death (Nedjat-Haiem et al., 2020). This awareness of one's impending death is a key facet of the experience of living with terminal cancer that could only be investigated and unpacked when focusing upon this specific patient group.

1.3. Philosophical Perspectives of End of Life

Within the wider context of the terminal cancer experience and the cancer-related distress and suffering associated with it, existential distress has been identified as a distinct facet of cancer-related distress (Philipp et al., 2021). Existential distress is more precisely described as the kind of distress that results from coming face to face with the core of existence, including questions about dying, life's purpose, being alone, one's own freedom, and life choices, as well as one's own sense of self-worth (Yates & Kissane, 2003). Existential philosophy and philosophers such as Heidegger and Kierkegaard offer a useful lens to consider the experience of living with terminal cancer as those living with life-threatening illnesses such as terminal cancer often experience significant existential distress due to their impending death resulting in meaninglessness (Morita et al., 2000; Griffiths et al., 2002; LeMay & Wilson, 2008).

Kierkegaard who has been widely considered to be the ‘father of existentialism’ considered man to be an ‘existing individual,’ embodying the finite and infinite, the temporal and eternal (Friedman, 1982, p.11) and freedom and necessity (O’Leary, 2005). In one of Kierkegaard’s key works *The Concept of Dread* (1844; 1944, following translation), he highlighted that anxiety and dread in the context of existentialism is the ‘dizziness of freedom.’ This ‘freedom’ considered in this case by Kierkegaard refers to the endless abyss of possibilities that, although imaginable, is incomprehensible by human finitude (Pullen & Rhodes, 2018). In his view, death is the only certainty within the human existence, it is an ‘uncertain certainty’ and may happen to humans at any time (Watkin, 1990, p.65). Kierkegaard highlighted that existential dread is a 'sympathetic antipathy' and 'antipathetic sympathy' which results in a feeling of both repulsion and attraction (Emmet, 1941). Dread, therefore, is a dialectic phenomenon as one experiences both attraction and repulsion due to the uncertainty associated with the future and possibility (Ebelendu & Onwuatuegwu, 2020). The dialectic nature of dread along with the awareness of uncertainty and of the abyss of possibility, is similar to the experience of uncertainty, ambivalence and ambiguity experienced by terminally ill patients at end of life (Gardner, 2008; Borneman et al., 2014) and viewing these issues through a philosophical lens allows us to truly comprehend the complex nature of the phenomenon of living with terminal cancer.

Kierkegaard's thoughts on the impact of the awareness of death offers insight into the spiritual dimension and development of man. Kierkegaard regarded the human self as essentially a spiritual being who has an awareness of their own finite existence and who is aware of their existence in relation to God and others (Lippitt & Pattison, 2013). Kierkegaard proposed three spheres of man's existence and it is the movement through these spheres that man seeks and finds happiness within (Evans, 2009). These spheres may also be termed as stages and represent differing levels of human spiritual development (Evans, 2009). During the first 'aesthetic' sphere of existence, man pursues eternal happiness through feelings of 'first love.' In this sphere there exists a tension between one's awareness of their finitude and the seeking of the eternal nature of beauty (Friedman, 1982, p.160). In the 'ethical sphere' of existence, a human may choose to exist in accordance with his own individual interest or in the interest of the universal world by living according to moral laws (Langdridge, 2007). In this sphere there exists a tension between the pursuit of one's own subjective happiness and leading a moral existence (Friedman, 1982).

The third sphere of existence is the ‘religious’ stage. It is here that man takes a passionate ‘leap of faith’ to ‘become subjective’ and thereby enter into a relationship with God through Christian faith and attain ‘eternal happiness’ (Schacht, 1973, p.310). This represents the highest possibility of selfhood for an individual, where an individual possesses increased self-awareness (Pojman, 1990). Kierkegaard proposed that it is through the experience of either guilt or despair that a human becomes aware of their level of existence and this may lead to one moving to a higher level (O’Leary, 2005). According to Kierkegaard, an individual cannot cure oneself from despair. It can only be overcome through finding faith in God and in finding peace and acceptance through a relationship with God (O’Leary, 2005). It may be considered that a human being’s progress through the three spheres of existence leads an individual towards living a life of increased integrity and to a more authentic form of human existence (Aiken, 1996).

A further philosophical lens that offers insight into the phenomenon of living with terminal illness is the Heideggerian lens. Heidegger’s (1927) main focus was on ‘being’ and he proposed that humans exist within the context of their environment ‘being in the world,’ which he termed ‘Dasein’ (Cerbone, 2011). Heidegger (1927) developed this concept of ‘Dasein’ or ‘being in the world’ to describe what it means for humans to make sense of the world and their place within it. For Heidegger, human beings exist in the world in the context of their environment and in their reciprocal interdependence with others (Conroy, 2003). ‘Being’ is described as being necessarily involved in, dependent upon the world and open to self-interpretation (Conroy, 2003). The concept of Dasein is represented by one's relationships, experienced by an individual being alongside the world, being with others and being one’s self (Horrigan-Kelly et al., 2016). Heidegger proposed that ‘Dasein’ was responsible for human’s pre-existing knowledge of their own world and therefore, it was not possible to understand anything outside of one’s own lifeworld and a universal truth was not possible (Sloan & Bowe, 2014). However, he believed that humans can attempt to make sense or find meaning in their own truth in their own lives as they experience a given phenomenon (Sloan & Bowe, 2014).

Building on this idea, Heidegger integrated social structures within his existential philosophical view through the introduction of the concept of ‘Mitsein’ or being with others (Knudsen, 2020). In contrast, a non-relational facet of being according to Heidegger is ‘being towards death.’ According to Heidegger, ‘being towards death’ acknowledges that one’s way of being must ultimately end, leading to a completion of an individual’s worldly existence and being in the world (Dreyfus & Wrathall, 2008). Heidegger conveys numerous important ideas in ‘being towards death,’ including the ideas that death is certain, non-relational, own-most, indefinite, and not to be outstripped (Foulds, 2014; Dreyfus, 1990). By this, Heidegger (1927) maintained that death can occur at any moment in one’s life, is experienced alone, there’s an uncertainty of time left and one’s death is an inevitable possibility (Vedder, 2008). As one is deprived of their supports and relationships, death is seen as an individual and a fundamental aspect of ‘Dasein,’ or one's being (Blattner, 2006). In Heidegger’s view, individuals who are confronted with their own mortality through a significant life event, such as life-threatening illness, may reflect more intensely on their finitude and awareness of their existence and develop a more authentic sense of self (la Cour & Hansen, 2012).

For Heidegger, an individual who lives in their authenticity recognises the temporal nature of their mortal existence and lives their life in a purposeful and meaningful way by having authentic awareness of the possibilities they have ahead of them (Dreyfus & Wrathall, 2008). Heidegger's 'call of conscience' posits that as one turns towards death authentically, one can transcend the suffering associated with one's knowledge of transience of life (Sepulveda, 2011; Gullick & West, 2020). Heidegger maintained that, while humans do not habitually reflect on the reality of their finitude, disruptions to normal life, such as illness, can result in the experience of anxiety due to the increased awareness of the limits to one's existence (Langdridge, 2007).

1.4. Living with Terminal Cancer

In addition to philosophical perspectives on end of life, research on terminal illness has shown that living with a terminal diagnosis represents a unique experience from a patient's perspective as one is aware that they have entered into the end-of-life phase, but still try to live their lives despite this knowledge (Bruce et al., 2014). MacArtney and colleagues (2017) highlighted that the experience of living with dying is a parallax experience whereby one is multiple things and understands two realities in this case, living and dying. Within death and dying literature, those living with terminal cancer have been highlighted as existing within liminal space between living and dying (Adorno, 2015; Lit, 2015; Willig & Wirth, 2018). Liminality refers to the 'betwixt and between' state between an old and new status or identity within a rite of passage (Turner, 1967; 1979, p.234). Studies from other contexts suggest that liminal space or periods are characterised by a sense of discomfort, uncertainty and ambiguity as one's former self is threatened and one's new state has not emerged yet (Gibbons et al., 2014). While this sense of uncertainty may cause further distress to patients at end of life (Morita et al., 2004), liminality may also enable one to transform through the suffering that one is experiencing and to live well with one's terminal disease (Lit, 2015).

Although those with a terminal illness, such as terminal cancer, may be considered as dying due to their life-threatening condition, participants may still have a 'will to live' during the terminal phase of their disease (Chochinov et al., 1999). While it is recognised that patients will face a challenge at this juncture in their lives, some patients can experience wellbeing while managing the symptoms associated with their illness (Wrubel et al., 2009). Similarly, Willig and Wirth (2018) posited that the liminal space between living and dying that is experienced by terminal cancer patients has the potential to cause suffering due to distress but also to create joy and a sense of fulfilment for patients. For example, Carter et al., (2004) highlighted that patients' began to 'take charge' of their lives once they were diagnosed with their terminal illness and they began to live with dying. Further, while patients can experience trauma as they confront their own mortality, they can also attempt to hold on to their lives and foster a meaningful existence, acknowledging the dynamic experience that is represented by 'living with dying' (Willig & Wirth, 2018).

However, it is acknowledged that living with terminal cancer often results in psychological distress, existential suffering and a reduced sense of wellbeing (Tang et al., 2014). Psychological suffering is one of the most significant issues that impacts the lives of those who are terminally ill at the end of life (Pessin et al., 2002). Transformation through suffering has been highlighted as a possibility for those at the end of life by existential philosophers such as Victor Frankl as well as by healthcare professionals like Saunders. Frankl (1985) maintained that the primary motivating factor for humans was to find meaning in life. Meaning could be found in love for others and through suffering. Where suffering was inevitable, Frankl asserted that one was responsible for one's attitude towards suffering. He also contended that nobody could advise another on what meaning meant to them; it was the task of each individual to find their own meaning in life. Cassell (1998) contended that transformation through suffering can only occur when the transcendent dimension of an individual is acknowledged. In light of these philosophical standpoints, transformation through suffering is a possibility for those at end of life however, one's spiritual and existential concerns need to be addressed in order for them to do so (Cassell, 1998).

Dame Cicely Saunders developed her philosophy of care, which has informed end of life care globally, on the understanding that individuals were physical and spiritual beings with an intrinsic value, who were in search of meaning in life. She considered spirituality at end of life as an inner journey towards finding meaning, peace and acceptance (Saunders, 1996). As spiritual pain experienced by individuals at end of life often manifests itself as the feeling of meaninglessness, it is essential that terminally ill patients gain the holistic support necessary to deal with this pain and continue to live despite their disease (Murata, 2003; Strang et al., 2004). In light of the highly idiosyncratic nature of terminal illness, the hospice movement was introduced by Saunders in the late 1960's to ensure that those dying received effective pain management care and focused upon providing dying patients with compassion and respect to conserve their dignity (Richmond, 2005). Saunders, founder of the hospice movement explained the concept of 'total pain' as being physical, emotional, social and spiritual in nature and noted the requirement for 'total care' within palliative care, where each need was addressed as one was dying (Saunders, 1996). With the support of others at end of life, Saunders (1988) posits that spiritual pain can be transformed by facing it and growing through the struggle, facilitating those who are terminally ill to live better at the end of their lives.

Despite this, research suggests that psychological distress is not acknowledged enough by medical professionals and is often undertreated among the terminally ill despite its high prevalence in this population (Thekkumpurath et al., 2008). A further issue identified within death and dying literature is existential suffering at end of life, which has gained increased traction in recent years (Breitbart et al., 2018; Philipp et al., 2021; Chen et al., 2022). Existential distress in those living with terminal cancer is often underpinned by physical, emotional or spiritual pain and may result in a lower quality of life, a poor mental and emotional state and suicidal ideation among those affected (Chen et al., 2022). Based on the increased psychosocial and spiritual distress that those with terminal cancer experience as they come to terms with their disease and try to cope with their impending death, they experience reduced levels of wellbeing and a reduced quality of life as they move towards death (Morris et al., 1986; Sherman et al., 2010; Bovero et al., 2016).

While it is known that terminal illness causes substantial burdens upon caregivers based on existing literature, the burden of terminal illness on patients themselves is not well understood within literature as terminal cancer patients often do not communicate with those around them at end of life about their illness and its terminal nature (Emanuel et al., 2000; Lewis et al., 2019; Fu et al., 2021). In light of existing findings, living with dying has been highlighted as an existential challenge for terminal cancer patients as they struggle to live their lives in the face of their impending death, the nature of experience is highly idiosyncratic as different patients may experience the terminal phase of their disease in different ways (Willig, 2015). Based on the highly idiosyncratic nature of the experience of living with terminal cancer, Willig and Wirth (2018) highlighted that further research is necessary provide deeper insights into different individuals' experiences of living with terminal cancer. Through gaining a better understanding of the experience of living with terminal cancer, one can gain further insight into the different dimensions of this dynamic experience and explore how terminal cancer patients can live their lives while dying.

1.5. Research Aims

In light of the literature discussed above and the recent call for further research identified by Willig and Wirth (2018) on gaining a better understanding of living with terminal cancer, the aim of this PhD thesis is to explore the phenomenon of living with terminal cancer from the perspective of patients themselves. Through exploring the lived experiences of terminally ill cancer patients, the findings of this study have the potential to contribute to literature by providing deeper insights into the experience of living with terminal cancer. Additionally, the findings of this research have the potential to inform future healthcare practice and policy to ensure that the relevant supports are provided to terminally ill cancer patients at end of life.

This PhD research consists of two studies. The first study consists of a qualitative meta-synthesis examining spirituality as experienced by terminal cancer patients. In order to gain insight into the experience of living with terminal cancer, it is essential to understand the psychosocial and spiritual needs of this population. While the psychosocial needs of late-stage cancer patients are generally well understood within literature with several reviews previously conducted focusing upon interventions to meet these needs (Badr, 2016; Teo et al., 2019; Warth et al., 2020), the spiritual care needs of patients living with terminal illness are not as well understood, despite being highlighted within literature as an important facet of care to consider at end of life (Vilalta et al., 2014). While systematic reviews have been conducted exploring both spiritual care needs and spiritual perspectives of patients at end of life (Williams, 2006; Edwards et al., 2010; Clyne et al., 2019) and spirituality as an aspect of the terminal cancer experience (Willig & Wirth, 2018), none have focused upon spirituality and terminal cancer patients specifically. While these reviews provide insight into the importance of spirituality at end of life, a comprehensive synthesis of existing literature is required to better understand the experiences of those living with terminal cancer and how spirituality may help them to cope and live with their illness. Hence, as part of this PhD research, a qualitative meta-synthesis examining spirituality as experienced by terminal cancer patients was conducted to further understand their experience of spirituality at end of life.

The second study in this PhD thesis aims to build on the findings of the first study by empirically exploring the experiences of those living with terminal cancer. This empirical study was deemed necessary as the experience of living with terminal cancer is not well understood and further research needs to be conducted to explore variations within the experience of living with terminal cancer due to the highly idiosyncratic nature of living with terminal illness, specifically cancer (Willig & Wirth, 2018).Stemming from the directions for future research identified in the meta-synthesis as well as those identified by Willig and Wirth (2018), the empirical study aimed to explore the phenomenon of living with terminal cancer from the perspective of patients themselves to gain further insight into the experience of living with terminal cancer. The researcher made the decision to focus upon participants who have been explicitly advised that they have entered the terminal phase of their cancer journey in order to understand the lived experience of terminal cancer and living with the knowledge of their reduced life expectancy and impending death. Through gaining an understanding of the lived experiences of those living with terminal cancer, the researcher can holistically gain insight into the phenomenon of living with terminal cancer in line with the aims of this PhD study.

It is hoped that the findings of this study can contribute to literature in the area of psycho-oncology by gaining a further understanding of the experience of those living with cancer through the lens of terminal cancer patients specifically. Further, it is proposed that the findings of this study may also contribute to healthcare practice and policy. These findings highlight the importance of patient-centered approaches to care at end of life and can inform the type of compassionate care required for those living with terminal cancer. Additionally, these research findings can inform survivorship programmes for this hidden population in the Irish context and beyond to improve the quality of life of those living with terminal cancer.

1.6. Thesis Structure

This thesis contains seven chapters. Chapter one is an introduction to the thesis which provides an overview of the background to this research, a definition of terminal cancer, brief justification for completing research in this area and an introduction to the research aims of the study. Chapter two comprises a comprehensive qualitative meta-synthesis examining spirituality as experienced by individuals living with terminal cancer. Chapter three presents the epistemological underpinnings and methodology of the empirical study. Following this, chapter four outlines the empirical methods and the specific procedure followed by the researcher during the empirical study completed as part of this PhD thesis. Chapter five presents the findings of this research following the comprehensive analysis of qualitative data. A critical discussion is provided in chapter six, viewing the findings of this research in light of existing knowledge. Finally, in chapter seven, the concluding chapter of this PhD thesis, the original contribution of this thesis is outlined, the significance of the findings presented are highlighted, the strengths and limitations of this study are acknowledged and future directions for research are provided.

Chapter Two:
Qualitative Meta-synthesis

"Live as if you were to die tomorrow. Learn as if you were to live forever"

Mahatma Gandhi.

Chapter Two

Qualitative Meta-synthesis

2.1. Introduction

This chapter focuses upon reviewing and synthesising the existing literature in the area of spirituality and terminal cancer. This specific patient population of terminal cancer patients has been identified as being an important population to consider as a terminal cancer diagnosis has been widely documented to have the potential to trigger psychological, social and spiritual concerns for patients as they move closer towards death. While several recent systematic literature reviews have been conducted on the psychological and social wellbeing of those living with advanced cancer, but not specifically terminal cancer, (Zimmerman et al., 2018; Teo et al., 2019; Lau et al., 2021), a comprehensive review focusing on spirituality and spiritual care has not been conducted since Edwards and colleagues' (2010) review. The focus of that review was on the role of spiritual care at end of life. Further, while former reviews have focused on psycho-spiritual wellbeing at end of life (Lin & Bauer-Wu, 2003; Wang et al., 2017), this study advances knowledge as it focuses specifically on spirituality as experienced by terminal cancer patients only. This is important and appropriate for this thesis as the experience of terminal cancer is unique and different from other experiences of cancer such as living with advanced or low-grade cancer as one is aware that their death is imminent. Additionally, it is important to consider spirituality in this population as it has been highlighted as an integral aspect of one's wellbeing at end of life (Sulmasy, 2002). A meta-synthesis was deemed as an appropriate method of synthesising existing literature on this topic as it can provide a more thorough and holistic understanding of a certain event or experience, namely living with terminal cancer (Sandelowski, 2012; Thorne et al., 2004). The aim of this qualitative meta-synthesis was to examine and synthesise existing evidence on spirituality as experienced by individuals living with terminal cancer.

2.2. Background to Qualitative Meta-synthesis

Due to factors such as global population growth and aging, the incidence of cancer and mortality rate are rising rapidly (Bray et al., 2018). By 2030, the number of cancer related deaths is predicted to increase to 13 million deaths annually (Fidler et al., 2018). A cancer diagnosis, its further progression and end of life phase can be causes of significant distress and suffering for individuals (Martins and Caldeira, 2018). Specifically, living with terminal cancer may be regarded as a particularly stressful experience (Chang et al., 2013). Distress may be experienced by such individuals in all dimensions (World Health Organization, 2021); physical (such as physical pain), psychological (depression or anxiety), social (loneliness or feelings of isolation), and spiritual (meaning, purpose and relationships) (Puchalski, 2002). The awareness of a reduced life expectancy may become a turning point by which individuals with terminal cancer begin to reflect on their own spirituality, relationships with others and God and to resolve spiritual issues within (Leung et al., 2006).

While religion is based on a shared set of practices and beliefs within a social institution (Dyson et al., 1997), spirituality is more individual in nature and is associated with transcendence, connection with a higher power and relationships that provide meaning and purpose (Siddall et al., 2015). Transcendence may be described as a feeling of connection with something which is greater than oneself (Breitbart, 2002). The International Consensus Conference on Improving the Spiritual Dimension of Whole Person Care defined spirituality as "a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions and practices" (Puchalski et al., 2014, p.646). Spirituality is a dynamic process that exists within an individual as they search for the sacred in their lives (Pargament, 1999). Both religion and spirituality have been found to have a positive impact on cancer patients' emotional wellbeing (Salsman et al., 2015), to help patients find meaning in their illness, to cope with existential issues and to elicit support from others within their social community (Jim et al., 2015). More specifically, religion and spirituality have also both been reported to play an important role in the wellbeing of individuals with terminal cancer (Bovero et al., 2016).

A spiritual perspective may be defined as "an expansion of personal boundaries through experiences such as prayer, forgiveness, belief in a power greater than oneself, and, for many, belief in a form of life after physical death" (Coward & Reed, 1996, p.281). The adoption of a spiritual perspective helps individuals to make sense of their lives based on the belief in, and a feeling of transcendence or connection with, a power greater than self (Haase et al., 1992). While spirituality is considered innate in all humans, a spiritual perspective differs among individuals in terms of the awareness that they may have of their own spirituality. Pivotal life events may be the precursor to individuals developing a spiritual perspective (Haase et al., 1992). A spiritual perspective helps individuals to frame these life events and determine their significance (Mohan

& Uys, 2006). Viewing life from a spiritual perspective may enable an individual to understand the process of personal growth, cope with adversity and to find meaning and purpose in life (Mohan & Uys, 2006). Research has shown that the adoption of a spiritual outlook by those living with a life-threatening illness helps them to find meaning, strength and comfort (Albaugh, 2003). A spiritual perspective has also been associated with self-transcendence in terminally ill patients and has been reported by medical professionals as having a significant and positive impact on patient well-being (Coward & Reed, 1996).

Following a terminal diagnosis, cancer patients often encounter psychological, social and spiritual distress (Adler & Page, 2008). Research has shown that their primary spiritual concerns at this point in the cancer trajectory are love, their relationships with others, their own life purpose (Ferrell et al., 2013) and their search for meaning as they attempt to make sense of a terminal diagnosis (Selby et al., 2016). A scoping review examining spiritual distress found that individuals living with terminal illness experienced a spiritual struggle, resulting in spiritual issues with others, within themselves and their own faith and with feelings of abandonment and anger with God (Roze des Ordons et al., 2018). Caldeira and colleagues (2014) in their study of elderly patients living with cancer, found that many individuals experience spiritual distress as they face the prospect of their death. This distress may manifest further as spiritual pain (Vasudevan, 2003), where feelings of meaninglessness, loss, hopelessness and despair can occur as patients live with terminal illness (Chen et al., 2018). The opportunity of spiritual growth may occur through the suffering of an illness (Tu, 2006). Through spiritual coping, research from other contexts has found that spiritual transformation can take place, resulting in a reformed view of an individual and their world and having a greater sense of purpose in life (Pargament et al., 2013).

Previous qualitative reviews have synthesised spirituality, the spiritual care needs and spiritual perspectives of patients at end of life (Clyne et al., 2019; Edwards et al., 2010; Williams, 2006). Other reviews have investigated spirituality as an aspect of the terminal cancer experience (Willig & Wirth, 2018). Previous meta-syntheses have also been conducted in the area of spirituality focused on the needs of family caregivers (Benites et al., 2021; Lalani et al., 2018), but none have focused specifically on terminal cancer patients. To the author's knowledge, this is the first meta-synthesis specifically examining spirituality in terminal cancer patients. For the purpose of this review, the author operationally defined terminal cancer as advanced cancer with a prognosis of less than a year.

The aim of this review was to examine and synthesise evidence on spirituality as experienced by individuals living with terminal cancer. This specific patient population has been identified as being important as a terminal cancer diagnosis has been widely documented to have the potential to trigger psychological, social and spiritual concerns for patients as they move closer towards death. The findings of this qualitative meta-synthesis can provide rich insights into the experience of living with terminal cancer and the potential impact that spirituality may have on the lives of those living with terminal cancer. Further, understanding the experience of spirituality among individuals living with terminal cancer can inform the type of compassionate end of life care and support that is needed to help individuals live while dying.

2.3. Method

Meta-syntheses are integrations that give new interpretations of discoveries and are more than the sum of their parts (Thorne et al., 2004). These interpretations are not present in any one study; rather, they are conclusions drawn from a sample of studies as a whole (Thorne et al., 2004). They provide a more thorough and holistic understanding of a certain event or experience (Sandelowski, 2012; Thorne et al., 2004). This systematic review and qualitative synthesis was conducted and reported in conformity with the requirements set out by the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) Statement (Tong et al., 2012) (See Appendix A). This review has been registered with PROSPERO (Registration no. CRD42021237406).

2.3.1. Search strategy

The search strategy drew upon search terms from an initial scoping search relating to definitions of spirituality and spiritual perspectives. Search terms were grouped into three categories; spirituality; terminal cancer; and qualitative. The search strategy consisted of a combination of controlled vocabulary (e.g. MeSH) and free-text terms (See Appendix B for search strategies). Boolean terms “OR” and “AND” were utilised to combine terms within and between the specified categories. The strategy was then adapted for each of six databases (PubMed, PsycINFO, CINAHL, Embase, Medline and Web of Science). The first database search was conducted on the 26th March 2020. Updated searches were completed on the 22nd March 2021 and 12th March 2022. The first two searches were screened by the PhD researcher

(LH) and second reviewer (EB). The screening for the final search was carried out by the PhD Researcher (LH) and an additional second reader (AD as EB was unavailable).

2.3.2. Selection Criteria

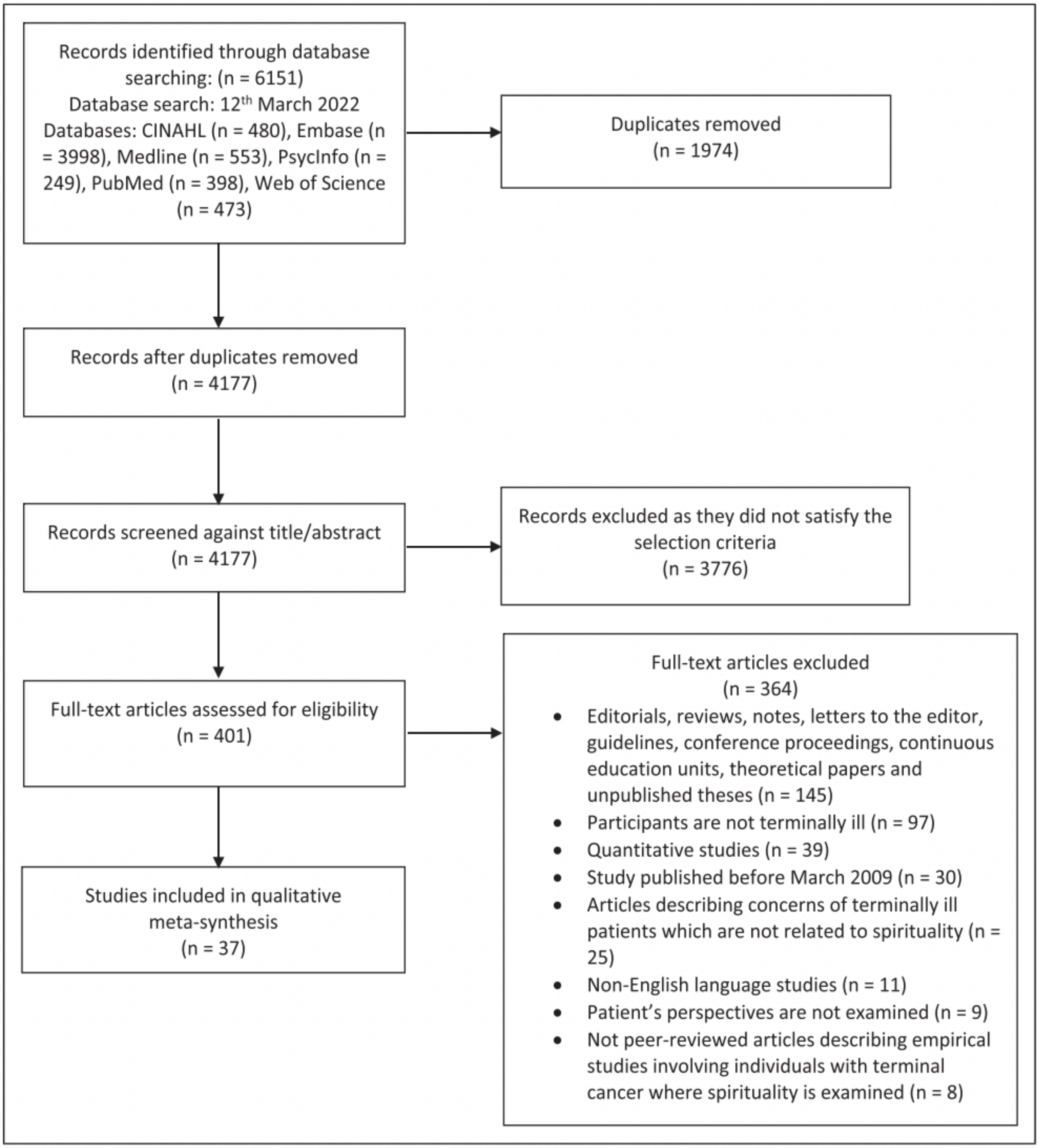
This review included empirical studies published between March 2009 and March 2022. Articles were selected for inclusion within the systematic review if they (1) were empirical studies published in English; (2) included adults of 18 years of age or older with a terminal cancer diagnosis; (3) included qualitative data relating to patients' perspectives on spirituality, spiritual perspectives or related concepts such as meaning making, existential distress, transcendence, religious perspective, sacred connections and personal growth. These concepts were drawn from the definition of spirituality from the International Consensus Conference on Improving the Spiritual Dimension of Whole Person Care (Puchalski et al., 2014), and from an initial scoping search relating to definitions of spirituality and spiritual perspectives. Mixed methods, intervention or quantitative studies with open-ended questions were included if qualitative data were reported separately. For the purpose of the review, the author defined terminal cancer as advanced cancer with a prognosis of less than a year, where there is an explicitly stated terminal diagnosis or where it can be inferred by a paper that participants are approaching end of life with advanced cancer.

2.3.3. Screening and full text review process

Following the exporting of searches from each database and subsequent removal of duplicate studies in Zotero™, the remaining titles and abstracts were imported by the first reviewer (LH) into systematic review software Covidence™. A two-stage screening and full text review process was undertaken. In the first stage, pairs of reviewers screened the titles and abstracts of included studies independently. LH and EB screened the studies for the first and second round of searches. LH and AD screened the studies for the final round as EB was unavailable. In the second stage, papers deemed as eligible from stage 1 were sourced as full texts and independently assessed for inclusion by LH and EB or AD.

Any disputes or discrepancies relating to the above were resolved through consensus between LH and EB or AD. Two other independent reviewers (SD, PG) were available for discussions to resolve any conflicts that were unable to be resolved. The reasons for exclusion for full text articles were recorded by the reviewers (LH, EB, AD) (See Figure 2.1 which highlights the review process and provides a summary of these reasons).

Figure 2.1. PRISMA flow diagram



2.3.4. Data extraction

The following data was extracted for each included study: author(s); country of study; aims of study; sample size; age range; setting; data collection method; and analytical approach. Data was extracted by LH and cross-checked by SD.

2.3.5. Quality appraisal

The Critical Appraisal Skills Programme (CASP) was adhered to by the reviewers when appraising the methodological quality of the included studies. All included studies were individually assessed by LH and EB or AD using the qualitative checklist examining methodological quality across 10 items including; results; methodology; research design; recruitment strategy; data collection; ethical considerations; and data analysis. Reviewers screened and rated each study using yes, no or can't tell based on each checklist item (CASP, 2021). Any disputes or discrepancies were resolved through consensus. Two other independent reviewers (SD, PG) were available to help resolve any conflicts that arose during this process.

2.3.6. Qualitative meta-synthesis method

The portions of the results and findings sections of the included studies that were relevant to the aims of this review were extracted by the first reviewer (LH) and entered into NVivo 12 software for data analysis. Thematic synthesis (Thomas and Harden, 2008) was utilised by the first reviewer (LH) in this qualitative meta-synthesis. The data was thematically synthesised using a three-stage framework; firstly, the line-by-line coding of relevant data; secondly, descriptive themes which remain close to the themes identified in the primary studies were developed according to patterns across the codes; and lastly, the development of analytical themes which go beyond the themes identified in the primary studies to produce a superior level of conceptual understanding and identify new concerns or recommendations relating to the topic being studied (Barnett-Page & Thomas, 2009). Each of the codes, descriptive themes and analytical themes were identified by the first author (LH) and validated by two further authors (SD, PG).

2.4. Qualitative Meta-synthesis Results

The systematic search yielded 6,151 articles. Following removal of duplicates by the first reviewer (LH), this left 4,177 articles for title and abstract screening. Following title and abstract screening by the first and second reviewers (LH, EB, AD), 3,776 of these articles were excluded as they did not satisfy the selection criteria. The remaining 401 full text articles were screened and 364 were removed as they did not satisfy the inclusion criteria. Following this screening, 37 articles were included in the review (See Figure 2.1).

2.4.1. Characteristics of included studies

Studies originated from the United States (USA) (n=9), the United Kingdom (UK) (n=4), Australia (n=2), New Zealand (n=2), Canada (n=2), Singapore (n=2), Denmark (n=2), China (n=2), India (n=2), Korea (n=2), Hong Kong (n = 1), Thailand (n=1), Israel (n=1), Norway (n=1), Georgia (n=1), Sweden (n=1), Taiwan (n=1), and Ireland (n=1). There was a combined total of 1,046 participants and of the 37 studies included, 35 provided a gender breakdown of participants (54% female and 46% male). Data collection methods included interviews (n=34), ethnography (n=1), a combination of interview and ethnography (n=1) and a case study of journal entries (n=1). Studies were classified into whether patients were at end of life (n=4), patients had terminal cancer (n=13), or patients had advanced cancer with a prognosis of less than twelve months (n=20). General characteristics of the included papers are included in Table 2.1.

Table 2.1.

Characteristics of included studies

Author (Year)	Country	Aim of Study	Sample (gender)	Age	Type of Cancer	Setting	Data Collection Method	Analytical Approach	Patient Classification
Adorno and Brownell, (2014)	USA	This exploratory study examined the perceptions of QOL from older veterans who were living with late-stage lung cancer.	12 (12m)	55-87	Late-stage lung cancer	Hospital	Semi-structured interviews	Grounded theory	Advanced cancer with a prognosis of <12 months
Alcorn et al., (2010)	USA	This study sought to inductively derive core themes of religion and/or spirituality active in patients' experiences of advanced cancer to inform the development of spiritual care interventions in the terminally ill cancer setting.	68 (32f, 36m)	Mean=60, SD=11.9	Not specified	Not stated	Scripted interviews	Grounded theory	Advanced cancer with a prognosis of <12 months
Aoun et al., (2016)	Australia	This study describes the lived experiences of older people coping with terminal cancer and living alone, focusing on how they face challenges of the biographical life changes from their disease progression.	43 (22f, 21m)	52-91	Lung, colorectal, breast, prostate, bladder, ovarian stomach and lymph nodes	Home	Semi-structured interviews	Thematic analysis	Terminal Cancer
Bentur et al., (2014)	Israel	This pilot study focused on identifying the coping strategies for existential and spiritual suffering at the end of life of secular Jews suffering from advanced-stage cancer	22 (14f, 8m)	39-76	Breast, lung, skin, stomach, pancreas, colon and neuro-blastoma	Hospital and home	In-depth interviews	Phenomenology	Advanced cancer with a prognosis of <12 months

Table 2.1.
Characteristics of included studies

Author (Year)	Country	Aim of Study	Sample (gender)	Age	Type of Cancer	Setting	Data Collection Method	Analytical Approach	Patient Classification
Best et al., (2014)	Australia	This study aimed to explore the nature of spiritual support for a group of Australian patients with advanced cancer, and ascertain their preferences regarding the role of doctors in helping them cope as they experience terminal illness.	15 (10f, 5m)	41-87	Stage IV pancreas, lung, prostate, Breast, colorectal, cervix and bladder	Hospital	Semi-structured interviews	Grounded theory	Advanced cancer with a prognosis of <12 months
Bruun Lorentsen et al., (2019)	Norway	The primary aim of this study is therefore to explore the patients' experiences of bodily changes in relation to dignity. The secondary aims are as follows: • What are the patients' experiences of the bodily changes? • How do the patients' experiences of bodily changes give insight into the phenomenon of dignity?	13 (9f, 4m)	53-83	Not specified	Hospital	In-depth interviews	Ontological hermeneutics	Cancer patient at end of life
Cao et al., (2020)	China	This study aimed to investigate the meaning of aftermath concerns in the process of preparing for dying among terminal cancer patients.	25 (13f, 12m)	36-84	Not specified	Hospital and Home	Semi-structured interviews	Thematic analysis	Terminal Cancer
Chikhladze et al., (2018)	Georgia	This study aimed to compare the attitudes, needs, and requirements at the end of life of the groups of	50 (34f, 16m)	Not stated	Not specified	Cancer Centre	Semi-structured interviews	Thematic analysis	Advanced cancer with a

Table 2.1.
Characteristics of included studies

Author (Year)	Country	Aim of Study	Sample (gender)	Age	Type of Cancer	Setting	Data Collection Method	Analytical Approach	Patient Classification
		patients with cancer and elderly individuals							prognosis of <12 months
Chittem at al., (2022)	India	This study aimed to understand Indian cancer patients' hopes and beliefs about the end of life, particularly focusing on how this informed their preferences regarding end-of-life treatment.	25 (7f, 18m)	27-72	Lung, stomach, colorectal, prostrate, breast, non-hodgkin lymphoma, acute lymphoblastic leukemia, cervix, endometrium, tongue cancer.	Hospital	Semi-structured interviews	Interpretative phenomenological analysis	Advanced cancer with a prognosis of <12 months
Cronfalk et al., (2009)	Sweden	The purpose of this study was to explore how patients in palliative home care perceive physical touch in the form of soft tissue massage, when they are dying	22 (14f, 8m)	41-76	Not specified	Home	In-depth interviews	Hermeneutic analysis and interpretation	Advanced cancer with a prognosis of <12 months
Duggleby et al., (2010)	Canada	The purpose of this study was to explore the current societal discourse on hope as well as the hope of older terminally ill cancer patients, their significant other, and their primary nurse	3 (2f, 1m)	62-82	Not specified	Home	Qualitative interviews	Critical discourse analysis	Advanced cancer with a prognosis of <12 months

Table 2.1.

Characteristics of included studies

Author (Year)	Country	Aim of Study	Sample (gender)	Age	Type of Cancer	Setting	Data Collection Method	Analytical Approach	Patient Classification
Egan et al., (2017)	New Zealand	This study aimed to investigate people's understanding of spirituality and spiritual care practices in New Zealand (NZ) hospices	24	Not stated	Not specified	Not stated	Semi-structured interviews	Thematic analysis	Advanced cancer with a prognosis of <12 months
Ellis et al., (2015)	UK	To explore the concept of suffering and distress by eliciting what individual patients with advanced cancer perceived as suffering and how they utilised their own resources to manage suffering	49	31-89	Advanced breast, colorectal and lung cancer	Home and Palliative Care day centre	Narrative Interview	Thematic analysis	Advanced cancer with a prognosis of <12 months
Elsner et al., (2012)	India	To investigate psychosocial and spiritual problems of terminally ill patients in Kerala, India	37 (22f, 15m)	26-65	Terminal breast and head-and-neck cancer	Home	Semi-structured interviews	Thematic analysis	Advanced cancer with a prognosis of <12 months
Eun et al., (2017)	Korea	The purpose of the current study was to gain insight into the perceptions of terminally ill cancer patients and their family members regarding a patient's end-of-life status and their need for Palliative sedation using qualitative, in-depth interviews	13 (5f, 8m)	32-81	Not specified	Healthcare facility	In-depth interviews	Thematic analysis	Terminal Cancer
Ginter, (2020)	USA	The aim of this qualitative study was to seek to understand the lived experiences of young women with metastatic breast	9 (9f)	28-40	Metastatic breast cancer	Home	Semi-structured interviews	Phenomenology	Terminal Cancer

Table 2.1.
Characteristics of included studies

Author (Year)	Country	Aim of Study	Sample (gender)	Age	Type of Cancer	Setting	Data Collection Method	Analytical Approach	Patient Classification
		cancer; in particular, the essence of their quality of life following their diagnosis							
Harmon, (2019)	USA	This auto/ethnography sought to exhibit the simple importance of a dog to the meaning making process for someone coming to terms with their mortality	1 (1f)	71	Breast and lung	Outdoor - Marina	Ethnography	Autoethnography	Cancer patient at end of life
Hughes et al., (2015)	New Zealand	The aim of the study was to explore how people who had been diagnosed with a terminal illness perceived and made meaning of palliative care, taking culture into account	8 (4f, 4m)	30s-70s	Not specified	Hospital and home	Ethnography/Semi-structured interviews	Grounded theory/thematic analysis	Terminal Cancer
Lee and Ramaswamy, (2020)	Singa-pore	The study examined and described the perspectives of people living with advanced cancer and the changes over time in their needs and experiences	11 (6f, 5m)	58-76	Not specified	Home	Semi-structured interviews	Interpretative phenomenological analysis	Advanced cancer with a prognosis of <12 months
Lee et al., (2013)	Singa-pore	This study examined the perceptions of dignified palliative care by a local population in Singapore?	4 (3f, 1m)	39-55	Advanced breast, thyroid and corpus uteri cancer	Home	Semi-structured interviews	Thematic analysis	Advanced cancer with a prognosis of <12 months
Li et al., (2014)	Taiwan	The purpose of this study was to explore the conceptualization of patients' dignity in the context of	9 (5f, 4m)	29-77	Not specified	Hospital and home	In depth interviews	Hermeneutic	Terminal Cancer

Table 2.1.

Characteristics of included studies

Author (Year)	Country	Aim of Study	Sample (gender)	Age	Type of Cancer	Setting	Data Collection Method	Analytical Approach	Patient Classification
		end-of-life care in Taiwan from both patients' and healthcare professionals' perspectives						interpretive analysis	
Liu et al., (2021)	China	This study aimed to explore the meaning of patient dignity at the end of life in traditional Chinese culture from perspectives of advanced cancer patients and their family members	15 (6f, 9m)	26-78	Myeloblastoma, Liposarcoma, Peritoneal cancer, Glioma, Rectal, Cardia, Liver, Breast, Stomach, Colon, Pancreatic Cancer and Chondrosarcoma	Hospital	Semi-structured interviews	Thematic analysis	Advanced cancer with a prognosis of <12 months
Maiko et al., (2019)	USA	To better understand the spiritual and religious strengths and distress of adults with advanced cancer	21 (14f, 7m)	Not stated	Not specified	Cancer Centre	Semi-structured interviews	Thematic analysis	Advanced cancer with a prognosis of <12 months
McTiernan and O'Connell, (2015)	Ireland	To explore how individuals with terminal cancer make sense of their dying experience within an Irish context	8 (6f, 2m)	36-68	Not specified	Home and Hospice	Semi-structured interviews (from public broadcasts)	Interpretative phenomenological analysis	Terminal Cancer

Table 2.1.
Characteristics of included studies

Author (Year)	Country	Aim of Study	Sample (gender)	Age	Type of Cancer	Setting	Data Collection Method	Analytical Approach	Patient Classification
Meisenhelder et al., (2016)	USA	To describe this young college student's experience of prayer in coping during a life-threatening illness	1 (1f)	19	Abdominal rhabdomyosarcoma	Not stated	Case study: journal entries	Case study analysis	Cancer patient at end of life
Mok et al., (2010)	Hong Kong	The aim of this study was to explore the phenomenon of spirituality and spiritual care among terminally ill Chinese patients	15 (8f, 7m)	53-89	Not specified	Hospital	In-depth interviews	Interpretative phenomenological analysis	Terminal Cancer
Nedjat-Haiem et al., (2020)	USA	This study examined the data using a guide developed from the concepts related to distress of a multifactorial unpleasant experience of a psychological, social, spiritual, and/or physical nature from a veteran's perspective.	27 (27m)	66-75	Not specified	Outpatient cancer clinic	In-depth interviews	Phenomenology	Advanced cancer with a prognosis of <12 months
Nilmanat et al., (2015)	Thailand	The objective of this study was to explore how Thai persons with advanced cancer move beyond suffering at the end of their life	15 (11f, 4m)	30-72	Cervical, urogenital, lung, breast, head-and-neck and colon cancer	Hospital and home	Case study: structured interview	Thematic analysis	Advanced cancer with a prognosis of <12 months
Peoples et al., (2018)	Denmark	The purpose of this study was to gain a deeper understanding of the ways in which people with advanced cancer who live at home perceive quality of life and	9 (5f, 4m)	57-85	Colon, breast, prostate, and endometrial cancer	Home	Semi-structured interviews	Thematic analysis	Advanced cancer with a prognosis of <12 months

Table 2.1.

Characteristics of included studies

Author (Year)	Country	Aim of Study	Sample (gender)	Age	Type of Cancer	Setting	Data Collection Method	Analytical Approach	Patient Classification
		any possible association with different dimensions of belonging							
Reeve et al., (2012)	UK	The aim of this study is to analyse these accounts from the perspective described in Illich's Medical Nemesis (1974) to see whether it offers any new insights into understanding and dealing with distress when living with terminal illness	27 (16f, 11m)	40s-80s	Breast, lung, gastrointestinal, haematological, head/neck, tongue, gynae, liver, urological	Hospital and home	Semi-structured interviews	Thematic analysis	Terminal Cancer
Reeve et al., (2010)	UK	To explore how well biographical theory supports the understanding of individual lived experience with terminal cancer	19 (11f, 8m)	40s-80s	Respiratory, haematological, gastrointestinal, urological, gynae, breast, and soft tissue	GP	Semi-structured interviews	Holistic form analysis	Terminal Cancer
Sherman et al., (2018)	USA	The current qualitative study sought to deepen our understanding of preparedness for EOL care, from the perspective of patients themselves	13 (6f, 7m)	Mean 63.8	Breast, lymphoma, prostate, lung, melanoma, head/neck, bladder, osteosarcoma, lipo-sarcoma	Not stated	In-depth Interviews	Thematic analysis	Advanced cancer with a prognosis of <12 months

Table 2.1.
Characteristics of included studies

Author (Year)	Country	Aim of Study	Sample (gender)	Age	Type of Cancer	Setting	Data Collection Method	Analytical Approach	Patient Classification
Thompson et al., (2009)	Canada	To identify the impact of prognostic acceptance or nonacceptance on the physical, psychological, and existential well-being of patients with advanced cancer	381 (212f, 169m)	Not stated	Lung, breast, genitourinary, gynaecologic, gastrointestinal and others	Palliative Care Unit	Semi-structured interviews	Thematic analysis	Cancer patient at end of life
Tuck et al., (2012)	USA	The threefold purpose of the study is to (a) explore the acceptability and feasibility of implementing the PATS (Presence, Active Listening, Touch, Sacred Story) intervention, an approach to narrative storytelling developed by the first author/principal investigator, and the administration of Spiritual Health Inventory (SHI; Highfield, 1992) in a sample of people who have a terminal diagnosis of cancer; (b) explore the experience of living with a terminal illness as expressed in the narratives of the sacred stories of the study participants that results from PATS; and (c) analyse the sacred stories for the presence and nature of spirituality and healing.	7 (3f, 4m)	Mean 59.5	Not specified	Hospital and home	Narrative interview: sacred story	Narrative analysis	Terminal Cancer

Table 2.1.

Characteristics of included studies

Author (Year)	Country	Aim of Study	Sample (gender)	Age	Type of Cancer	Setting	Data Collection Method	Analytical Approach	Patient Classification
Voetmann et al., (2022)	Denmark	The purpose of this study was to investigate how spiritual matters are communicated both verbally and non-verbally in the interaction between patient and HCP in two Danish hospices.	12 (8f, 4m)	Mean 61	Not specified	Hospice	Semi-structured interviews.	Interpretative phenomenological analysis	Terminal Cancer
Willig, (2015)	UK	This article has 2 aims. The first is to demonstrate how the application of an innovative qualitative methodology generated novel insights into the experience of living with advanced cancer. The article's second aim is to challenge the idea that the identification of shared themes provides the researcher with access to the meaning and significance of the experience of "living-with-dying."	3 (3f)	Mid 30s - early 80s	Not specified	Cancer Centre and Home	Semi-structured interviews.	Hermeneutic phenomenological analysis	Advanced cancer with a prognosis of <12 months
Yoon Sun Kim, (2021)	Korea	The purpose of this study was to examine the life-sustaining treatment decisions of terminal cancer patients.	10 (4f, 6m)	61-75	Liver and biliary tract cancer, lung cancer	Healthcare Facility	In-depth interviews	Phenomenological analysis	Terminal Cancer

2.4.2. CASP quality appraisal

Table 2.2. provides the results of the CASP quality appraisal. All included studies (n=37) yielded a ‘yes’ rating for criteria relating to research aims, appropriateness of methodology, research design, recruitment strategy, data collection, research findings and value of the research. Where studies reported insufficient information regarding a specific criterion, they received a ‘cannot tell’ rating. Criteria receiving ‘cannot tell’ ratings included: relationships between the researcher and participants (n=18), whether data analysis was sufficiently rigorous (n=1) and ethical considerations (n=1). However, this may have been a reporting feature within a given article rather than a lack of research quality. On this basis, studies were deemed of a medium to high quality when they did not receive any ‘no’ ratings (indicating a low quality) and were therefore included in the meta-synthesis.

2.4.3. Thematic synthesis findings

Four analytical themes relating to an individual’s experience of spirituality while living with terminal cancer were generated: making sense of dying, living with dying, feeling connected and being reflective. Analytical and associated descriptive themes are presented in table 2.3. Illustrative quotes are presented in table 2.4.

Table 2.2.
CASP quality assessment of included studies.

Author (Year)	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. How valuable is the research?
Adorno and Brownell (2014)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes
Alcorn et al., (2010)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes
Aoun et al., (2016)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Bentur et al., (2014)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes
Best et al., (2014)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes
Bruun Lorentsen et al., (2019)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Cao et al., (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Chikhladze et al., (2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Chittem et al., (2022)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes

Table 2.2.

CASP quality assessment of included studies.

Author (Year)	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. How valuable is the research?
Cronfalk et al., (2009)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Duggleby et al., (2010)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes
Egan et al., (2017)	Yes	Yes	Yee	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Ellis et al., (2015)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes
Elsner et al., (2012)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes
Eun et al., (2017)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes
Ginter (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Harmon (2019)	Yes	Yes	Yes	Yes	Yes	Yes	Cannot tell	Cannot tell	Yes	Yes
Hughes et al., (2015)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Lee and Ramaswamy (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Table 2.2.

CASP quality assessment of included studies.

Author (Year)	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. How valuable is the research?
Lee et al., (2013)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes
Li et al., (2014)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Liu et al., (2021)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes
Maiko et al., (2019)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
McTiernan and O'Connell (2015)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes
Meisenhelder et al., (2016)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes
Mok et al., (2010)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Nedjat-Haiem et al., (2020)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes
Nilmanat et al., (2015)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Table 2.2.

CASP quality assessment of included studies.

Author (Year)	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. How valuable is the research?
Peoples et al., (2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Reeve et al., (2012)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes
Reeve et al. (2010)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes
Sherman et al., (2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Thompson et al., (2009)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes
Tuck et al., (2012)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Voetmann et al., (2022)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes
Willig (2015)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Yoon Sun Kim (2021)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Table 2.3.

Overview of analytic and descriptive themes

Analytic themes	Descriptive themes
Making sense of dying	Spiritual distress
	Meaning making
	Maintaining a sense of purpose
	Changing identity
Living with dying	Finding acceptance
	Living with hope
	Living in the present
Feeling connected	A feeling of connection to self
	Feeling connected with family and friends
	Feeling connected with nature and animals
	Feeling connected with a higher power
Being reflective	Life review and legacy
	Reflecting on the transformation journey

Table 2.4.

Overview of analytic themes, descriptive themes and illustrative quotes

Analytic themes	Descriptive themes	Illustrative quotes
Making sense of dying	Spiritual distress	"They don't even want to hear ... if I talk positive, they are pretty good, but if I talk negative, they don't want to hear that other outcome, what it could be or whatever. They refuse to listen to it and that angers me some too because I'm trying to prepare them and prepare myself too." (Adorno & Brownell, 2014:139) "Seeing my family suffer looking at me . not being able to be in control of my own destiny" (Ellis et al., 2015:204) "One thing I dread is being on my own. I am not frightened to die, but I am frightened of dying, I don't want to go through all this pain." (Egan et al., 2017:227) "If I am destined to die, please let me die without suffering." (Eun et al., 2017:1013) "The only thing is, I don't know what the future's going to be. Do I want to know? … Maybe I'm a coward and I don't want to know yet. Just take every day as it comes. And that's, really that's all you can do isn't it? ... I've got it, what can I do about it? Get on with it … I'm no special person. I'm one of many. I'm a pinhead in the universe … I am a fatalist you know. I believe what has to be, will be … I feel quite peaceful. It's there. I can't do anything about it." (Reeve et al., 2010:186). "We need a good farewell. We all know the truth, but no one wants to openly talk about it and just wait until the last minute. Some families even didn't get a chance to say goodbye" (Liu et al., 2022:4).
	Meaning making	"All my priorities and my perspective on life changed, I say those who haven't been there don't even understand what life is… I think people these days are too busy with material things and confuse the unimportant things with the essence." (Bentur et al., 2014:4) "It's made me completely and utterly totally change my outlook, my philosophy, my way of life, my behaviours, to some extent my morals as well has changed." (Reeve et al., 2012:149)
	Maintaining a sense of purpose	"I'm saying there's nothing stronger than the power of daily routine. For me, managing to keep the routine going, waking up in the morning with the kids and putting them to bed, sending them off to kindergarten with a smile, reading them a story… [is] supreme bliss. Supreme." (Bentur et al., 2014:4)

Table 2.4.

Overview of analytic themes, descriptive themes and illustrative quotes

Analytic themes	Descriptive themes	Illustrative quotes
		“I have that feeling [the feeling of meaningless-ness]. After the diagnosis I felt like that. Before that I didn’t feel like that because I earned more and we had a lot of fish and money. When I fall I can recognize the fall of my family also” (Elsner et al., 2012:1185).
	Changing identity	“I don’t want to talk about it all the time. I don’t want to be the girl that has cancer. It is mine, I wear it, I accept it. But, I’m not a side-show.” (Sherman et al., 2018:461).
		“I have started to think that my body is my house and that I still am situated in my body. I try to imagine nice pictures of my body. A house is a good place where you are happy, safe and taken care of. It is a place filled with warmth and love…. I have started painting. I feel that is important for my identity now… By doing this I feel that I have moved into new rooms deeper in my body.” (Bruun Lorentsen et al., 2019:1167)
		“Why can’t it be somebody else?” (McTiernan & O’Connell, 2015:644)
Living with dying	Finding acceptance	“This growing acceptance of life as it is, with all the sorrow, the pain, the suffering and the tragedy, has brought me a kind of peace” (Mok et al., 2010:364).
		“I want to be prepared for death, so I need to face the reality that I’m not going to live” (Hughes et al, 2015:177)
		“I just keep thinking that God has a plan, and if this is it, I’m accepting” (Maiko et al, 2019:582)
		“Adopting the Buddhist teaching on the truth of life helped the informants move on and be at peace with themselves. Just think that as a human being, birth, aging, sickness, and death are there. I We can’t escape from it (death) the poor die, so do the rich. This is the same world for everyone. We were once born, and we will once die. This is how I tamjai. We have to accept the way things are.” (Nilmanat et al., 2015:227).
		“And it [death] had a lot of focus for me in the beginning. I may have gotten use to it by now, I think. Although it doesn’t make it better, though. I think I have gotten use to it. A little bit of everyday life has come into it” (Voetmann et al., 2022:3).
	Living with hope	“I hope that it would go quietly, peacefully, with as little pain as possible …” (Duggleby et al., 2010:364)
		“The day you lose hope is the day you start to die. I’m not ready to give up my hope yet.” (Ginter, 2020:429)
		“To me, hope keeps my mind alive, and inspires my will to live.” (Nilmanat et al., 2015:228)

Table 2.4.

Overview of analytic themes, descriptive themes and illustrative quotes

Analytic themes	Descriptive themes	Illustrative quotes
		"You've got to have faith and a positive outlook because it is going to help you last longer." (Alcorn et al., 2010:583). "At least right now, our end result really isn't really going to be a cure. It's more about long-term coping and maintenance and how long can we run with it. And I feel like the longer we hold on to our hope, the better we are going to be." (Ginter, 2020:429). "It's not about cancer…it's not, it's not…anything else. It's your day-to-day life. If you don't have hope, you don't have life" (Chittem et al., 2022:2519). "…Anyway, I will get over this. So I don't think yet I am losing this battle. I still think I will win. I will not lose hope" (Yoon Sun Kim, 2021:104).
	Living in the present	"I really just am living day to day right now … and not so much focusing on planning for the future. It makes it a lot easier to sort of cope with having, you know, a quote unquote, 'terminal disease' or whatever." (Ginter, 2020:428) "I am living my life, not my death." (McTiernan & O'Connell, 2015:645) "I need to be in harmony with myself and the universe. I don't know what will happen tomorrow, but I will try to be happy today." (Mok et al., 2010:364) "It teaches you to live for today" (Reeve et al., 2012:149) "What we need to do is to resign ourselves to our fate, just let it be." (Li et al., 2014:2925).
Feeling connected	A feeling of connection to self	"The bodily changes have helped me calm down and become aware of what is important in life." (Bruun Lorentsen et al., 2019:1166) "I am in a very difficult situation the massage helped me to gain strength." (Cronfalk et al., 2009:1205) "[Yoga] was cathartic, giving me that quiet time with my mind, just being able to be thankful for what I did have, you know, the life that was there." (Ginter, 2020:426) "In the past, I was scared of some things. Like, it never would've occurred to me ever to get a tattoo in a million years. But I feel like at this point, it's a way of being able to control my body and taking sort of ownership of something. And at this point, I figured, you know, my body's been through so much. I have scars. I have all sorts of stuff. Why not add a tattoo? You're only going to live once." (Ginter, 2020:427)

Table 2.4.

Overview of analytic themes, descriptive themes and illustrative quotes

Analytic themes	Descriptive themes	Illustrative quotes
	Feeling connected with family and friends	“I believe in human strength, in human contact. Not as a cliché, on a true level… I think that now, around the illness, I have succeeded in reaching levels with people that are so much deeper than just the written word.” (Bentur et al., 2014:3)
		“People say death is a most personal and lonely journey. However, I have found that when there is a connected relationship with me, in the journey of dying, it gives me a lot of courage and encouragement” (Mok et al., 2010:364)
		“Well, [cancer] weeded out the superficial friendships and enhanced the lifelong friendships that are the ones that are really meaningful. Most people, if they don’t experience things like this, it’s kind of like a filter that weeds out, like I say, the superficial friends and the true friends, are the cream that come to the top” (Maiko et al., 2019:578)
	Feeling connected with nature and animals	“I enjoy the seasonal change in my garden. I see it as the meaning of life that things grow and perish. It’s the same with us, we grow up and then we die. It just takes us a bit longer” (Peoples et al., 2018:206)
		“I can’t live without my dog. I wouldn’t be happy without my dog.” (Aoun et al., 2016:361)
		“I prefer to remain at home with family and animals” (Aoun et al., 2016:361)
		“It has to do with the meaning of life, that there is something that is bigger than oneself. Maybe that is why I’m so comfortable in nature.” (Peoples et al., 2018:206)
	Feeling connected with a higher power	“I don’t know if I will survive this cancer, but without God it is hard to stay sane sometimes. For me, religion and spirituality keeps me going.” (Alcorn et al., 2010:584)
		“I’ve been more spiritually hungry now than I was on my first diagnosis. Because … I knew was going to survive. Which is why I didn’t really bother. And now, it’s like, well, maybe I should reconsider this.” (Ginter, 2020:428)
		“You believe in God, you got everything.” (Best et al., 2014:1335).
		“I think it’s important, but especially important in the situation I’m in. It would be very difficult if I didn’t have any sense of spirituality.” (Egan et al., 2017:226)
		“Through the years I’ve turned my back on my God. Tried to do things on my own. Since my illness I’ve called on him to help me through this.” (Maiko et al., 2019:579)
		“Religion is SO important…it’s important to have a relationship that, to know or to believe that it’s not the end. And that, that is the most comforting thing you can have.” (Sherman et al.,

Table 2.4.

Overview of analytic themes, descriptive themes and illustrative quotes

Analytic themes	Descriptive themes	Illustrative quotes
		2018:461). “God will show me the way,” (Tuck et al., 2012:76). “They had a song – the Queen song ‘I don’t want to live forever’, at the end, and I said ‘That’s my song’, but I’m going to have ‘I want to break free’ at the beginning....and I don’t want them to cry, it’s not sad. They should be happy that I’m relieved...released you know.” (Aoun et al., 2016:361). “Keeping faith in God that’s it, and taking treatment, after all…it is God’s decision. There is nothing in our hands. Getting this disease is not in our hands, so, we need to be strong” (Chittem et al., 2022:2520). “I don’t want to be in pain when I die. However, I feel comfortable when I am beside God. So I am not afraid of dying. You wouldn’t imagine the power of faith” (Yoon Sun Kim, 2021:104).
Being reflective	Life review and legacy	“I had a few things that I always said I wanted to be a part of, and I achieved that, and everything is alright now… You want to see your children settled and financially secure …that their lives will be fine. I wanted a grandson, and he’s coming.” (Bentur et al., 2014:4) “I have regrets in things that I did wrong, which I don’t have the opportunity to put right, and I wish to goodness I had.” (McTiernan & O’Connell, 2015:645) “I have completed my responsibilities as a father as I have worked hard and supported the family.” (Mok et al., 2010:364) “When a person gets a death sentence, it makes me look back how I have lived, and I tend to think more” (Yoon Sun Kim, 2021:103).
	Reflecting on the transformation journey	“It’s a transformative experience to have an illness such as this, and when you have that you have to re-evaluate all you’ve done in life, who you are, and who you’re going to be.” (Alcorn et al., 2010:584) “People who knew me before I was ill can’t believe the transformation that I’ve gone through. I’m much calmer, less het up” (Reeve et al., 2012:149) “This cancer has really changed me. I used to be really hard, now I’m softer. I want to just live every day I have now, not thinking about when I’ll die, but just live each moment” (Hughes et al., 2015:175)

Table 2.4.

Overview of analytic themes, descriptive themes and illustrative quotes

Analytic themes	Descriptive themes	Illustrative quotes
		‘You feel black. You feel ‘why me?’ And you can’t do things. I was angry, very angry - extremely angry.’… ‘I don’t know. I mean I’m happy as Larry now. I still have my down days. I still get down…And I think now, well heh hey so it’s a house! Why do you need to be rushing? I don’t run for buses anymore! You know – if I miss a bus. Well ok, there’ll be another in a few minutes. As long as the lads have got clothes on their back. Meals in the house. That’s it.’ (Reeve et al., 2010:189)

2.4.3.1. Making sense of dying

Many participants across the included studies reported initial feelings of spiritual distress as they attempted to live with dying. As participants endeavoured to make sense of dying, spirituality was found to help them find new meaning and appreciation of life while living with terminal illness, to live with purpose and to live with a changed identity.

Spiritual Distress

The experience of spiritual distress was identified by participants of several included studies, as they attempted to make sense of dying. When faced with the reality of living with terminal illness, participants in four studies struggled with being confronted with their mortality (Chittem et al., 2022; Ellis et al., 2015; Willig 2015; Yoon Sun Kim, 2021) and in another study, participants suffered from existential angst (Egan et al., 2017). Some participants from other included studies also experienced feelings of injustice at the unfairness of having a terminal illness, with questions of ‘why me?’ and ‘why now?’ (Egan et al., 2017; McTiernan & O’Connell, 2015; Reeve et al., 2010; Reeve et al., 2012; Thompson et al., 2009).

Many participants in included studies feared suffering associated with death (Eun et al., 2017; Sherman et al., 2018). Participants of several studies not only experienced a fear of dying, but also feared and grieved leaving behind family members and friends (Cao et al., 2020; Chittem et al., 2022; Egan et al., 2017; Liu et al., 2021; Maiko et al, 2019; Thompson et al., 2009; Tuck et al., 2012; Yoon Sun Kim, 2021). Feelings of loneliness and loss were experienced by participants in further studies, which they perceived as difficulties experienced with family members (Maiko et al., 2019; Thompson et al., 2009; Tuck et al., 2012) and friends who were fearful of their illness and ceased the friendships (Aoun et al., 2016). For participants of some included studies, the ultimate loss was perceived as experiencing the sadness and suffering of their loved ones (Cao et al., 2020; Ellis et al., 2015; Maiko et al., 2019; Thompson et al., 2009).

In five studies, participants reported that they experienced difficulties in communicating their grief about a future that they would no longer share with families (Adorno & Brownell, 2014; Bentur et al. 2014; Elsner et al. 2012; Ginter 2020; Liu et al., 2021). The inability of some family members to accept and speak about the impending death of their loved ones contributed to the suffering of participants in further studies (Adorno & Brownell, 2014; Eun et al., 2017; Sherman et al., 2018).

Meaning Making

Spirituality contributed to participants finding meaning within their illness and to cope in their daily lives. During the course of their illness, participants in two studies found that their perspective on life had changed and this was reflected in what gave life new meaning (Alcorn et al., 2010; Lee et al., 2013). For participants in three further studies, this was found in the routine of everyday life and time spent with the family (Bentur et al., 2014; McTiernan & O'Connell, 2015). Connection with family and friends and the strengthening of relationships provided powerful meaning for participants in one study (Mok et al., 2010). In this study, meaning was also found through participants acknowledging the good that they had done in their lives and having no regrets (Mok et al., 2010). In another study, meaning was found also through spiritual practices such as meditation, prayer and daily rituals (Egan et al., 2017). In two further studies, meaning was also experienced in the transience of nature, which reflected the natural flow of life, where things grow, flourish and then die (Mok et al., 2010; Peoples et al., 2018). In one study, participants struggled with the existential challenge of finding meaning in their lives as they attempted to live while dying (Willig, 2015). Through learning to live with uncertainty of the future, participants in another study found new meaning in their approach to life and their appreciation of it (Reeve et al., 2012).

Maintaining a Sense of Purpose

Living with a sense of purpose was found to be of significance to participants as they attempted to make sense of dying. This was achieved through keeping a sense of purpose or in some cases, finding new purpose through connection with others. Participants in one study wished for continuity and routine in their daily lives as a means of maintaining purpose (Reeve et al., 2010). Adorno and Brownell (2014) found that the physical symptoms of late-stage cancer prevented participants from partaking in activities which helped them cope with stress in life and which provided them with purpose and a sense of identity, of 'who I am.' For participants in another study, lack of purpose led to a sense of uselessness and meaninglessness (Elsner et al., 2012). Being able to contribute to the lives of others, such as supporting friends and family members, enabled participants in three further studies to live with a sense of purpose (Bentur et al., 2014; Peoples et al., 2018; Thompson et al., 2009). Being perceived by others as a good person was reported by participants as being an important aspect of ones' life purpose in another study; the sense of connection, respect and value that it created was an important inner spiritual resource when living with terminal illness (Mok et al., 2010).

2.4.3.2. Changing Identity

The diagnosis of terminal illness also led to changes in identity participants' perceptions and experiences of their identity in three studies (Lee et al., 2013; McTiernan & O'Connell, 2015). In one study, while a number of participants experienced a loss of their own identity, others began to perceive themselves in a more spiritual light (Maiko et al., 2019). Participants in two further studies commented on the change in their identity and were concerned with the stigma associated with it (Reeve et al., 2012; Sherman et al., 2018).

2.4.3.2. Living with dying

As participants attempted to live with the knowledge of their shortened life expectancy, they began to accept they were dying. In many cases, such acceptance was found through spirituality, such as connection with oneself and one's inner strength, connection with others, spiritual beliefs and transcendence. Hope was identified as an important resource to maintain positivity during illness in the face of death. Previous hopes for a cure were replaced with hope for comfort and a peaceful death, without suffering. Living in the present moment helped participants to live with dying, instead of worrying about the future.

Finding Acceptance

Spirituality was found to help participants to find acceptance of living with the knowledge that their cancer was terminal. As participants lived with the reality of the terminal status of their illness, they moved towards acceptance of their shorter life expectancy. For instance, in Maiko and colleagues' study (2019), participants used acceptance through positive thinking and accessing their own inner sources of strength as they attempted to live with the reality of their terminal illness. Aoun and colleagues (2016) found that many participants accepted their death through ‘biographical closure’ where death was normalized as they approached the end of their lives without fear. The finding of acceptance through the normalization of death was also found by authors in seven further studies (Hughes et al., 2015; Liu et al., 2021; Maiko et al., 2019; Thompson et al., 2009; Tuck et al., 2012; Voetmann et al., 2022; Yoon Sun Kim, 2021). Acceptance of dying was found through many means, including feeling love and support from family and friends (Adorno & Brownell, 2014; Lee et al., 2013; Thompson et al., 2009), spiritual beliefs, faith and practices and a belief in the afterlife (Alcorn et al., 2010; Maiko et al., 2019; Thompson et al., 2009). In some cases, participants experienced difficulties in finding acceptance due to fears of leaving loved ones behind (Adorno & Brownell, 2014) and worries of becoming a burden on family (Aoun et al., 2016; Elsner et al., 2012; Lee et al., 2013; Liu et al., 2021; Yoon Sun Kim, 2021). Participants in another study moved towards a greater acceptance of their imminent death through surrendering control of their lives to a transcendent power (Mok et al., 2010). When participants accepted death as a part of the process of life, it helped to create a sense of peace within them (Mok et al., 2010; Nilmanat et al., 2015; Tuck et al., 2012). Professional spiritual support through palliative services was also reported as an important component of facilitating acceptance (Thompson et al., 2009).

Living with Hope

Living with hope was found by the authors of some studies to be an aspect of spirituality which assisted participants in living with terminal cancer. Hope was noted by the authors of some studies an as important inner resource used by participants to help themselves to keep positive throughout the course their illness. In five studies, participants continued to ‘keep fighting' in the hope of overcoming their illness, despite knowing the prognosis (Bentur et al., 2014, Chittem et al., 2022; Hughes et al., 2015; Tuck et al., 2012; Yoon Sun Kim, 2021). Participants in further studies expressed the need for faith and positivity in the hope of living longer (Adorno & Brownell, 2014; Alcorn et al., 2010; Eun et al., 2017). In two studies, participants hoped that medication would either stop the growth of the cancer or extend the length of their lives (Hughes et al., 2015; McTiernan & O'Connell, 2015). Participants in other studies held out hope for a cure, despite knowing their terminal condition (Alcorn et al., 2010; Lee & Ramaswamy, 2020; Nilmanat et al., 2015; Thompson et al., 2009). Where suffering increased, participants in two studies hoped for a peaceful death without suffering (Eun et al., 2017; Lee & Ramaswamy, 2020). Others hoped for an afterlife (McTiernan & O'Connell, 2015). The continuation of treatment meant hope for participants, while the end of treatment was associated with death in one further study (Adorno & Brownell, 2014). During the progression of their illness, participants' hopes of being cured were replaced with hopes for comfort and peace for themselves and their families at the end of life in two studies (Duggleby et al., 2010; Meisenhelder et al., 2016). Hope was shifted from recovery and finding a cure to focusing on maintaining a better quality of life during the remaining course of their illness in a further study (Lee et al., 2013). In one study, participants reported that they moved between hope and a sense of hopelessness as they struggled to live with dying (Lee & Ramaswamy, 2020).

Living in the present

Living in the present, by being mindful of the present moment, is an aspect of spirituality which was identified by participants in many studies as helping them to live with dying. In one study, many participants decided to live in the present, rather than plan for the future, as a means of living with their terminal illness (Ginter, 2020). While a terminal illness diagnosis was identified by Reeve and colleagues (2010) as a ‘biographical disruption’ in participants’ lives, continuity in the flow of life was achieved through living life in the present, where participants found comfort in completing daily activities. McTiernan and O’Connell (2015) found that participants lived with dying by focussing on living life, rather than dying. Living life on a daily basis and deciding to maintain a positive approach to life were important factors in helping participants to live with their prognosis (Bentur et al, 2014; Liu et al., 2021; Maiko et al., 2019; Nedjat-Haiem et al., 2020; Thompson et al., 2009; Tuck et al., 2012; Voetmann et al., 2022). Through living in the present, participants reported an increased appreciation of what they found to be meaningful in their lives (McTiernan & O’Connell, 2015). Li and colleagues (2014) found that living life to the full during their illness helped participants to maintain their dignity. Through continuing to live their lives instead of worrying about their prognosis, participants of another study recognised the importance of living each moment of every day as they lived with dying (Hughes et al., 2015). Lee and Ramaswamy (2020), however, found that while living in the present was reported by many participants in the earlier stages after diagnosis helped them to continue with their lives, for participants whose health physically deteriorated, this was replaced by a sense of meaninglessness as the disease progressed.

2.4.3.3. Feeling connected

Spirituality was experienced by participants in included studies through experiences of feeling connected to oneself, others, animals, nature, transcendence and God or a higher power. Connection to self was reported by participants as helping to reduce physical discomfort, while connections with friends and family members were identified as an important source of spiritual support as participants lived with terminal cancer. A connection to nature and animals was considered to have a positive impact on participants' wellbeing. Connection with God or a higher power facilitated participants to find spiritual strength and comfort while living with terminal cancer. Engaging in spiritual practices provided participants with comfort, distraction from physical symptoms and a sense of calm.

A feeling of connection to self

The experience of a harmonisation of self, through integrating one's physical, emotional and spiritual health was identified by participants as being of significant benefit to their wellbeing while living with terminal cancer. Specifically, three studies found that, where the integration of spiritual, mental and emotional wellbeing was experienced, participants found it easier to cope with physical difficulties (Bentur et al., 2014; Nilmanat et al., 2015; Ginter, 2020). Some practices to facilitate such an integration were found in two studies and these included yoga, meditation, mindfulness, hypnosis (Ginter, 2020) and massage (Cronfalk et al., 2009). Bruun Lorentsen and colleagues (2019) found that some participants equated the physical changes in their body to an 'existential journey' through the course of their illness. Also, in this study, participants reported visualizing and connecting with their body in a new light as a means of maintaining dignity and preserving their identity (Bruun Lorentsen et al., 2019). The experience of integration and harmonisation of the self through mind, body and spirit was found to provide existential respite for participants in one study, where feelings of meaninglessness were replaced with a sense of existential wellbeing and reduced anxiety and loneliness (Cronfalk et al., 2009). Through this connection, participants in another study gained a sense of control and ownership of their bodies and became more comfortable within themselves (Ginter, 2020). Through connection with their body, participants in a further study realized for themselves that death was near (McTiernan & O'Connell, 2015).

Feeling connected with family and friends

Several included studies reported the importance of meaningful relationships with family members and with friends. Here, connections with friends and family were found to be an important source of spiritual support. The experience of living with terminal cancer enabled participants to move away from superficial relationships and to deepen the more meaningful relationships in their lives in four studies (Adorno & Brownell, 2014; Hughes et al., 2015; Lee et al., 2013; Maiko et al., 2019). In three studies, participants reported a strengthening of connections with family and close friends following a terminal diagnosis and a deeper sense of meaning being created between themselves and their loved ones (Lee et al., 2013; Maiko et al., 2019; Willig, 2015). Participants in four further studies reported a strong need to feel connected with others and this connection provided them with an increased sense of wellbeing (Bentur et al., 2014; Chikhladze et al., 2018; Lee & Ramaswamy, 2020; Peoples et al., 2018); in one of these studies, this was especially the case for family members, whose happiness and wellbeing were deeply connected to that of their own (Bentur et al., 2014). Relationships with family and friends were also reported as being important factors in providing meaning in life for participants in two studies (Bentur et al., 2014; Lee & Ramaswamy, 2020). Li and colleagues (2014) reported that being loved by others had a substantial impact on participants' ability to maintain their dignity. For most participants in Adorno and Brownell's (2014) study, their 'greatest worry' was for their family members. Participants also prepared themselves to be reunited with their loves ones after death (Aoun et al., 2016). Relationships with family and friends were regarded as sources of spiritual strength or support in five studies (Best et al., 2014; Lee et al., 2013; McTiernan & O'Connell, 2015; Mok et al., 2010; Nilmanat et al., 2015). In Tuck and colleagues' study (2012), connections with others enabled participants to talk about their prognosis and to search for answers.

Feeling connected with nature and animals

Spirituality as experienced through a connection with animals and nature was reported by participants as having a positive impact on their wellbeing in many included studies. In three studies, a connection to pets (Aoun et al., 2016; Harmon, 2019; Thompson et al., 2009) was reported by participants as providing comfort to them, as they lived with terminal illness. Participants of three studies also experienced comfort through spending time in nature (Aoun et al., 2016; Elsner et al., 2012; Peoples et al., 2018). Spending time in nature with animals was found to help participants in coming to terms with their own mortality in two studies (Aoun et al., 2016; Harmon, 2019). In Harmon's (2019) study in particular, dogs were found to provide therapeutic support through a meaningful connection and their relationship with people. Aoun and colleagues (2016) reported that the company of animals was a factor in participants' decisions to remain living at home and in maintaining independence; participants in this study also reported that a spiritual connection to nature influenced where they chose to die. Thompson and colleagues (2009) found that participants experienced difficulty in facing the prospect of leaving their pets behind in distress following their death. Nature provided participants with the opportunity to feel a sense of existential belonging and spiritual connection and to reflect upon the transience of life in a further study (Peoples et al., 2018). For those who were unable to spend time in nature, a deep sense of disconnection from the world was experienced by participants in one study (Elsner et al., 2012).

Feeling connected with a higher power

The experience of feeling a connection to a higher power was found to be an important way of finding meaning in illness, in gaining acceptance and finding peace within among participants in included studies. This feeling of a connection to a higher power through religious and spiritual beliefs had a significant influence on how participants lived with their illness across many included studies (Alcorn et al., 2010; Aoun et al., 2016; Best et al., 2014; Chittem et al., 2022; Egan et al., 2017; Ellis et al., 2015; Elsner et al., 2012; Ginter, 2020; Lee & Ramaswamy, 2020; Lee et al., 2013; Li et al., 2014; Liu et al., 2021; Maiko et al., 2019; McTiernan & O'Connell, 2015; Meisenhelder et al., 2016; Mok et al., 2010; Nedjat-Haiem et al., 2020; Nilmanat et al., 2015; Reeve et al., 2012; Sherman et al., 2018; Tuck et al., 2012; Yoon Sun Kim, 2021). In three studies, participants reported initial feelings of anger and disappointment for being let down or abandoned by God (Maiko et al., 2019; McTiernan & O'Connell, 2015; Reeve et al., 2012), while in another study, participants reported that they were being tested by God (Nilmanat et al., 2015). In three studies, participants reported that a terminal diagnosis resulted in an increased connection with God (Elsner et al., 2012; Ginter, 2020; Maiko et al., 2019). Maintaining a relationship with and faith in God was acknowledged by participants as an important aspect of living with terminal illness in six studies (Alcorn et al., 2010; Aoun et al., 2016; Egan et al., 2017; Lee et al., 2013; Nedjat-Haiem et al., 2020; Tuck et al., 2012). In further studies, a relationship with God or a transcendent being was reported as being a source of spiritual strength for participants (Alcorn et al., 2010; Best et al., 2014; Liu et al., 2021;

Meisenhelder et al., 2016) and as a means of coping emotionally (McTiernan & O'Connell, 2015). In five studies, participants reported that a relationship with God provided them with an important source of comfort during their illness as they prepared for end of life (Alcorn et al., 2010; Ellis et al., 2015; Lee & Ramaswamy, 2020; Sherman et al., 2018; Yoon Sun Kim, 2021). Religious beliefs were reported by participants of further studies to help participants to live with terminal illness (Alcorn et al., 2010; Chittem et al., 2022; Lee et al., 2013; Maiko et al., 2019) and to find peace within (Mok et al., 2010). 'Having faith in God's will' assisted participants of one study to gain peace of mind in the face of death (Nilmanat et al., 2015). 'Resignation to God's will' was reported by participants of two studies as a means of maintaining dignity at the end stages of terminal illness (Lee et al., 2013; Li et al., 2014). The belief in an afterlife was reported by participants of further studies to provide comfort (Alcorn et al., 2010; Ginter, 2020) and peace (Mok et al., 2010).

Religious and spiritual practices were used by participants as a means of connecting with a higher power while living with their illness in two studies (Alcorn et al., 2010; Meisenhelder et al., 2016). Participants of five studies reported that engaging in prayer and meditation were used as a positive means of coping (Alcorn et al., 2010; Ginter, 2020; Hughes et al., 2015; Meisenhelder et al., 2016; Tuck et al., 2012). In one study, participants reported that prayers were not only intended for cancer survivors themselves, but also for their families (Alcorn et al., 2010). In further studies, prayer was reported by participants as providing them with a sense of comfort (Aoun et al., 2016), distraction and relaxation (Elsner et al., 2012). Talking to God was reported by Lee and colleagues (2013) as providing a sense of calm, in helping participants sleep and to be effective in managing pain. In addition, participants of two studies felt comforted by the prayers from their spiritual community (Elsner et al., 2012; Maiko et al., 2019) and participants of another study reported that they appreciated the practical assistance that the community offered (Sherman et al., 2018).

2.4.3.4. Being reflective

Reflecting on one's mortality, the life that was lived and the meaningful connections created with others were identified by participants in included studies as important aspects of spirituality at the end of life. Through this reflection, many of these participants identified the need to heal unresolved wounds with others from the past, create legacies to connect with future generations and to prepare for death with their loved ones. As participants reflected on their illness and their shortened life expectancy, many reported a transformation in their outlook towards life, in their meaning of life and in finding peace and acceptance in dying.

Life review and legacy

In many included studies, spirituality, as experienced by those living with terminal cancer, involved reflecting on one's own mortality, re-evaluating one's life history, appreciation of life (Alcorn et al., 2010; Mok et al., 2010; Yoon Sun Kim, 2021) and previous life choices and decisions (Hughes et al., 2015; McTiernan & O'Connell, 2015). Time was identified as a facilitator for participants of one study, which enabled them to complete essential life tasks and make pivotal decisions (Voetmann et al., 2022). Participants of four studies reported having 'unfinished business' with others, such as organizing personal affairs (Tuck et al., 2012), and saying goodbye to loved ones and dealing with relationships (Hughes et al., 2015; McTiernan &

O’Connell, 2015; Sherman et al., 2018). Unresolved issues, such as regrets over previous wrongdoings and worries about leaving family members, resulted in the experience of suffering among participants in two studies (Egan et al., 2017; McTiernan & O’Connell, 2015). In one study, participants reflected on the future generations that they would not have an opportunity to meet and created several types of legacy documents for family members as gifts and memories, including DVDS, photographs, journals and films (McTiernan & O’Connell, 2015). In other studies, creating keepsakes, memoires and gifts for great-grandchildren, created a sense of connection with future generations of family and existential hope for the future among participants (Hughes et al., 2015; Peoples et al., 2018). Saying goodbye to close friends and family members, sharing personal belongings with loved ones, making a will and planning funeral arrangements were means by which some participants of further studies found closure to their lives as they prepared for death (Aoun et al., 2016; Bentur et al., 2014; Ginter, 2020; Hughes et al., 2015). In one study with Chinese participants, the preparing of a shroud in which to be buried was used to help participants to create a sense of togetherness with family, to prepare for death and to serve as a spiritual support for participants as they prepared for death (Cao et al., 2020).

Reflecting on the transformation journey

Through reflection on their mortality and the re-evaluation of their lives as they journeyed towards death, some participants in included studies identified a transformation in their outlook towards life, their experience of meaning of life and their peaceful acceptance of death. Participants in one study reported that they found their illness to be a transformative experience (McTiernan & O’Connell, 2015), while participants of two further studies reported that this experience changed how they viewed the world in a meaningful way (Alcorn et al., 2010; Reeve et al., 2010). Ellis and colleagues (2015) found that, through their suffering, participants experienced a spiritual transformation, which enabled them to gain a deeper understanding of themselves and a greater ability to cope with their illness. Transcendence, a feeling of being connected with something which is greater than oneself, was reported by participants of one study as being an important spiritual need at end of life (Chikhladze et al., 2018). In another study, transcendence occurred as a transformation in the way participants connected with their family (Hughes et al., 2015) and in a further study, transcendence was experienced by participants in their renewed outlook on life (Reeve et al., 2012). For participants of another study, transcendence was achieved through finding peace, harmony and serenity within. Transcendence was gained by participants through connection with self, others and God and in finding meaning and acceptance of death (Mok et al., 2010). Nilmanat and colleagues (2015) found that faith and trust in God, being hopeful and being surrounded by the love and care of family enabled participants to move beyond and transcend distress and suffering and to achieve peace.

2.5. Discussion of Meta-synthesis Findings

This is the first meta-synthesis specifically examining spirituality in terminal cancer patients. Furthermore, this meta-synthesis addressed the lack of clarity that often surrounds the difference between advanced cancer and terminal cancer by operationalising the definition of terminal cancer to provide a basis for this meta-synthesis. This specific population has been identified as being important as a terminal cancer diagnosis may potentially trigger psychological, social and spiritual concerns for patients as they move closer towards death. Understanding the experience of spirituality among individuals living with terminal cancer can inform the type of compassionate end of life care and support that is needed to help individuals live while dying.

Four analytical themes relating to an individual's experience of spirituality while living with terminal cancer were generated. These included *Making Sense of Dying*, *Living with Dying*, *Feeling Connected* and *Being Reflective*. These findings demonstrate the difficulties experienced by those suffering from spiritual distress and highlight how the experience of spirituality could positively impact an individual's life through one's sense of meaning, purpose and identity. The findings also show that individuals living with terminal cancer can continue to live their lives despite knowledge of their finitude through acceptance, hope and living in the present moment. These findings suggest that connection to oneself, others, nature and a higher power helped participants to find meaning in their illness and lives. The findings also suggest the potentially transformative impact of self-reflection on ones' outlook on life and on dying; specifically, these aspects of spirituality were reported by participants as being beneficial in living while dying, to help in overcoming suffering, finding a deeper understanding of self and meaning in life, gaining acceptance of illness and death, and achieving inner peace.

While previous reviews in the area of spirituality highlight the importance of meeting the spiritual care needs for patients at end of life (Clyne et al., 2019; Edwards et al., 2010), this meta-synthesis offers a unique contribution to literature in the area as it specifically examines spirituality as experienced by terminal cancer patients. Further, it demonstrates the transformation that an individual may experience in dealing with increased distress and finding peace of mind. This meta-synthesis suggests that spirituality may act as a catalyst in experiencing this transformation from suffering to peace. In addition, the findings of this meta-synthesis highlight the tension that exists between the distress of meaninglessness and the spiritual comfort that may be achieved through personal growth. In some studies included in this meta-synthesis, this transformation was referred to by participants as an existential or a transformational journey. These findings mirror those within previous research, where this transformation has been referred to as a spiritual journey (McGrath, 2004).

The findings of this meta-synthesis also demonstrate how individuals may struggle to make sense of the situation that they are in and its consequential meaning following a terminal diagnosis. Individuals living with terminal illness may experience feelings of fear, anxiety, hopelessness, frustration and desperation due to uncertainty about their future (Tarbi & Meghani, 2019; Wang et al., 2018). While previous research indicates that religion or spirituality may not always have a positive effect on individuals with terminal cancer (King, 2012), this review identifies spirituality as a means through which an individual may navigate through the uncertainty of their cancer journey and it highlights how transcendence from suffering may occur through transformation of self. Previous literature has identified spirituality as a means of helping individuals to make sense of a terminal diagnosis (Ford et al., 2012), to live with the uncertainty of their cancer journey (Balboni et al., 2007) and to find meaning within their lives (Guerrero-Torrelles et al., 2017; Visser et al., 2010; Young et al., 2015). Although none of the articles examined in this review specifically reported on the use of spiritual perspectives for participants to find meaning and purpose while living with terminal cancer, participants in these studies talk about the core components of spirituality without explicitly using the term itself. Therefore, these findings suggest that viewing one's life through the lens of spirituality may prove to be beneficial for individuals as one engages in reflection towards the end of one's life.

These findings also demonstrate the potential that spirituality has to enable individuals to find meaning and purpose in their lives. The findings highlight that spirituality may act as a catalyst in facilitating individuals with terminal cancer to experience strengthened relationships with the self, family, society, nature, and a higher power. It highlights the importance of relationships and connections in the process of meaning making at end of life. The findings of this meta-synthesis are similar to previous literature in terms of the focus of spirituality being on meaning and significant relationships, however these studies did not exclusively focus on terminal cancer patients (Breitbart, 2002; Gijsberts et al, 2019). The findings also support previous studies which noted that relationships play a pivotal role in meaning making and finding acceptance (Rego et al., 2018; Sand et al., 2009).

The findings indicate that hope and living in the present may be used by individuals as means of coping and as ways of living with dying. Individuals may retain a sense of hope, despite knowing that there is no cure available. Previously held hopes for the future may be replaced with the creation of new hopes which are deeper and more fulfilling. Hopes may include the strengthening of relationships, leaving a legacy behind and being well remembered (Ferrell & Coyle, 2010). Furthermore, hope may play a pivotal role in enabling people with terminal cancer to live their lives in a more meaningful manner. Living in the present may enable an individual to accept the inevitability of terminal cancer and to live life in a meaningful way, despite difficulties that may be experienced. This corresponds with studies in other contexts which have shown that completing everyday activities such as undertaking chores offers individuals a sense of purpose and enables them to show their capability and competence despite being ill (la Cour et al., 2009). Living in the present, while maintaining a sense of purpose, allows individuals to feel they are not just a patient nor defined by their illness and there are other aspects to their lives beyond dealing with their symptoms (Breitbart, 2002).

This meta-synthesis highlights the important role of relationships in the experience of spirituality in the lives of those living with terminal cancer. Relationships and meaningful connection with self, others, nature and God are identified as significant dimensions of spirituality. Individuals may utilise the connection between themselves and others, nature, animals and a higher power as a means of living with the reality of their impending death. Previous research suggests that the existential isolation experienced by individuals with terminal cancer motivates them to value the relationships they have in their lives (Strang et al., 2001). The findings suggest that connections with family, friends and religious communities have been valuable sources of emotional support at end of life, in line with findings of previous reviews (Edwards et al., 2010; Weathers et al., 2016). The findings indicate that individuals who maintain a relationship with God may feel a sense of comfort and feel less lonely. Individuals utilise their relationship with a higher power as a source of strength, support and comfort. This finding is supported by previous research (Scott et al., 2014; Sulmasy, 2006).

End of life is identified as an important time of reflection of one’s values, relationships and a search for meaning. The findings of this meta-synthesis suggest that the process of reflection offers individuals living with terminal cancer the opportunity to consider their lives and their relationships with others. This review highlights a common wish for individuals at end of life to resolve all unfinished business or unresolved disputes within one's life in order to move towards living with a sense of peace at end of life. Previous studies on advanced cancer patients suggest that individuals wish to resolve these issues to minimise any negative ultimate outcomes such as guilt, regret and remorse (Masterson et al., 2018).

The findings of this meta-synthesis highlight the need for interventions and programmes that promote the wellbeing of those with terminal cancer. Evidence suggests that individualised interventions are necessary to match the specific needs of terminal cancer patients to help them cope with their illness, manage symptoms and find meaning in their lives (Teo et al., 2019). Further, previous research suggests that there is need for the integration of person-centered spiritual care into healthcare services (Selman et al., 2018). Studies have shown that there is a requirement for basic spiritual care training for all palliative care staff with more advanced levels of spiritual care to be offered by more highly skilled professionals (Selman et al., 2018). This review supports these findings due to the individualised and dynamic nature of both spirituality and suffering as experienced by individuals with terminal cancer. Additionally, these findings may inform the type of compassionate end of life care and support that is needed to help individuals live while dying.

There are several strengths and limitations of the current meta-synthesis. As indicated above, this qualitative meta-synthesis provides a unique contribution to existing literature in the areas of spirituality and terminal cancer as it highlights that spirituality can be a transformative experience that helps individuals to experience peace at end of life through acceptance, hope and living in the present. It also highlights the importance of relationships in meaning making and living well at end of life which may result in increased wellbeing in terminal cancer patients. A challenge associated with this meta-synthesis was the lack of clarity surrounding the difference between the terms ‘advanced’ and ‘terminal’ cancer in relevant literature; in response to this, the researcher focused on the perspectives of terminal cancer patients with less than 12 months prognosis in the inclusion criteria. While the provision of these definitions is an inherent strength within this study, it is acknowledged that this study is limited to describing results of individuals from this group only. Hence, additional studies addressing the perspectives of caregivers, healthcare professionals and other patients who may have had advanced cancer with a longer projected prognosis were not included during the screening stage of this review. Additionally, a further limitation associated with this meta-synthesis is that only peer-reviewed journal articles published in the English language were included in this review. In future research, it would be beneficial for authors to clearly define the meaning of advanced cancer and to include whether participants have been explicitly advised if they have entered the terminal phase or not. This is an important issue to consider as the terms are currently used interchangeably which causes a lack of clarity within the literature. Further research in this area would be beneficial in providing a holistic understanding of the perceived spiritual needs of terminal cancer patients from the perspectives of caregivers, healthcare professional and patients. Further research in this area focusing on patients would be both significant and valuable as their perspectives are provided from those living with terminal cancer rather than other stakeholders within their lives and can provide a deeper insight into their spiritual and existential concerns as they live with the knowledge of their reduced life expectancy.

2.6. Conclusion

The findings of this qualitative meta-synthesis highlight how the experience of spirituality can positively impact the lives of terminal cancer patients. The findings also demonstrate the multi-dimensional and dynamic nature of spirituality as individuals attempt to live with dying. They provide evidence that spirituality can be a transformative experience that allows individuals to experience peace at end of life through acceptance, hope and living in the present. Meaning in life may be found through relationships and connections with self, family, friends, nature, animals and God or a higher power. Through finding meaning in life and connection, participants experience increased wellbeing. These findings may inform the type of compassionate end of life care and support that is needed to help individuals live while dying.

The findings of this meta-synthesis provide insight into the experience of living with terminal cancer and the experience of spirituality from the perspective of patients themselves. As former reviews had considered the psychosocial needs of those living with terminal cancer, this qualitative meta-synthesis provides a rich insight into the experience of spirituality in the lives of those living with terminal cancer. The findings of this qualitative meta-synthesis suggest that the experience of spirituality can be a transformative experience and enhance the wellbeing of terminal cancer patients. Despite these findings, other studies suggest that terminal cancer patients continue to experience difficulty in living their lives well due to a lack of understanding of their unique needs and symptoms (Teunissen et al., 2007; LeMay & Wilson, 2008). Hence, an empirical study was also conducted in addition to this qualitative meta-synthesis to provide a deeper understanding of the lived experience of people living with terminal cancer. Although the subject of the meta-synthesis was more specific than that of the empirical study due to the need for a comprehensive review in the field of spirituality and terminal cancer, the findings of this meta-synthesis influenced the research approach taken by the researcher in the empirical study in this thesis. The definition of terminal cancer developed by the researcher in this meta-synthesis informed the inclusion criteria for participation in the empirical study, specifically focusing on those living with advanced cancer with a prognosis of less than 12 months. This was important to consider as the experience of terminal cancer is unique and distinct from other cancer experiences as these participants are living with the knowledge of their impending death. The findings of this meta-synthesis and those of the empirical study will be considered together to further our knowledge on the experience of living with terminal cancer, in line with the aims of this PhD research.

Chapter Three:
Methodology

“Reality is created by the mind, we can change our reality by changing our mind”

Plato.

Chapter Three

Methodology

3.1. Introduction

This chapter outlines the background and the aims and objectives of the empirical study as well as the methodology adopted in this research. Firstly, the background to the empirical study will be presented and the research aims of this study will be introduced. Following this, an outline of the qualitative approach taken in this research will be provided. This will be followed by an explanation and justification for the interpretivist paradigmatic stance taken in this project. Further, an overview of phenomenology (including descriptive and hermeneutic phenomenology) will be provided with a focus on the specific methodology being utilised in this study, interpretative phenomenological analysis (IPA). Finally, researcher positioning and reflexivity will be acknowledged and discussed.

3.2. Background to the Empirical Study

The experience of terminal cancer has been highlighted as a complex and multidimensional experience for those living with this incurable disease (Tang et al., 2014). For terminal cancer patients, the awareness of their approaching death may lead to emotional, social, and spiritual distress as patients attempt to come to terms with their advancing illness and move towards death (Ross & Austin, 2013; Martins & Caldeira, 2018; Kyoda & Kanda, 2019). Lundquist (2019) posited that a dichotomy exists between how those living with advanced cancer are perceived and how they feel while living with their illness. This contrast is also reflected in the context of terminally ill patients, as LeMay and Wilson (2008) suggest that existential distress and spiritual suffering are important aspects of care to consider at the end of life, but healthcare professionals have a limited understanding of these facets of wellbeing among terminally ill patients.

Based on these research findings, it is important to gain a better understanding of the experience of living with terminal cancer to appreciate and comprehend the complexity of this experience and the vast range of concerns that terminal cancer patients have at end of life. This is crucial and relevant for the purposes of this dissertation, as the experience of terminal cancer is distinct from other cancer experiences, such as experiencing advanced or low-grade disease because one has the knowledge that their death is imminent. Additionally, it is different to other illnesses as the focus of care is no longer on prolonging life and providing curative treatment, but on symptom management and ensuring one lives and dies with dignity and has a ‘good death’ (Leung et al., 2010; Cottrell & Duggleby, 2016; Hayden et al., 2020).

While following a terminal diagnosis the focus of one’s care centres upon a having ‘good death,’ research suggests that the focus of terminal cancer patients turns to living a ‘good life,’ despite their terminal disease (Carter et al., 2004). Following a terminal diagnosis, patients are often left in liminal space as they attempt to come to terms with this news and experience the existential paradox of living while dying (Coyle, 2006; Willig & Wirth, 2018). Liminal space refers to “transitional phases in a human’s life; phases that involve ambiguity and the dissolution of order that open a fluid or malleable space in which new ideas, practices and identities may emerge and develop" (Liedgren et al., 2023, p.1; Turner, 1974). Studies have highlighted that liminality is a significant dimension of the terminal cancer experience as one attempts to live with the knowledge of their impending death (Ho et al., 2013; Adorno, 2015; Willig & Wirth, 2018). While one may experience increased distress and death anxiety as they come to terms with the "frailness of existence" (Sand et al., p.13), one may also focus upon living the best life they can in the time that they have remaining with the awareness of dying (Arantzamendi et al., 2020). The phenomenon of 'living with dying' has gained recent attention within literature and has been highlighted as being characterised by both universal and idiosyncratic features (Willig, 2015; Brose et al., 2023). Hence, it is essential to consider individual lived experiences to gain a deeper understanding and rich insights into nuances associated with this phenomenon.

Based on the findings of the qualitative meta-synthesis conducted in the first phase of this PhD research project and recent calls by Willig and Wirth (2018) for further research exploring the phenomenon of living with terminal cancer to be conducted, it is evident that the experience of living with terminal cancer is not well understood within existing literature and needs to be examined further to understand the true complexity of this experience. While the former studies have examined this phenomenon in advanced cancer patients (Arantzamendi et al., 2020; Brose et al., 2023), there is a need for further examination of the lived experience of terminal cancer specifically from the perspective of patients themselves to further understand this phenomenon and gain a rich insight into the different experiences participants have, due to the idiosyncratic nature of this experience (Willig, 2015; Willig & Wirth, 2018). Hence, the second phase of this PhD research will include an empirical investigation of the lived experience of terminal cancer. Specifically, this empirical study will aim to explore the phenomenon of living with terminal cancer from the perspective of patients themselves, in line with the central aims of this PhD thesis. In order to gain an understanding of the lived experience of terminal cancer, a qualitative approach will be utilised.

3.3. Qualitative research

Qualitative research has gained significant attraction and has risen in popularity since the late 1900s (Alasuutari, 2010). Miller (2016, p.777) defines qualitative research as "an approach to research that is primarily concerned with studying the nature, quality, and meaning of human experience." The purpose of qualitative research, according to Merriam and Tisdell (2015), is to better understand how individuals interpret their experiences and the meaning they derive from them. This approach to empirical research does not seek to establish differences between groups, cause-effect relationships or test given hypotheses, but aims to gain a better understanding of the social world and the social and psychological processes that occur within it in an inductive manner (Willig, 2019). Hence, qualitative research aims to understand the 'how' and 'why' behind a given phenomenon rather than 'what' or 'when' associated with quantitative or deductive research (Creswell, 2014). As the aim in qualitative studies is to gain insight beyond appearance or surface-level information and delve into the meanings attributed with given experiences or events, an in-depth investigation of a small number of cases is often associated with a qualitative approach (Crouch & McKenzie, 2006). As generalisability is not the core focus of most qualitative research, a large sample is not required for qualitative studies (Leung, 2015). Further, the purposive small samples associated with qualitative research have been identified as a strength of the approach rather than a limitation, given the rich knowledge that is obtained from participants (Smith, 2017).

Renjith et al., (2021) highlighted that qualitative research offers a significant contribution to health literature as it provides insights into complex phenomena through the rich and detailed description of individuals’ accounts of their experiences, that quantitative approaches would not be able to convey in the same way. Qualitative approaches to research are particularly impactful in the study of health and illness as they facilitate researchers in gaining an in-depth understanding of the issues that health care practitioners and patients face in their own context (Sorrell, 2013). Further, the use of qualitative research provides researchers with an insight into the lifeworlds of their target population (including patients, caregivers or healthcare practitioners) and to analyse facets of complex healthcare experiences that have not yet been explored (Braun & Clarke, 2019). Qualitative methods have been identified as an effective method of exploring complex phenomena and personal experiences at end of life specifically (Strang, 2000). Similar studies have identified that qualitative methods have enabled other researchers to understand how one makes sense of a cancer diagnosis and how they focus on trying to attribute meaning to the phenomenon of living with dying (Willig, 2015).

According to Merriam and Tisdell (2015), the purpose of qualitative research is to better understand how individuals interpret their experiences and the meaning they acquire from these experiences. In contrast to numerical or quantitative data, qualitative data is frequently collected orally or in writing (Polkinghorne, 2005). Qualitative research designs allow researchers to thoroughly examine a particular phenomenon in great detail (Eshlaghy et al., 2011). As they enable participants to convey their own individual and unique experience of health and illness, qualitative research designs are frequently employed in the field of health research (Astin & Long, 2014). Instead of quantifying the impact of an intervention or change across time, a qualitative research design attempts to provide researchers with a better understanding of their phenomenon of interest (Green & Thorogood, 2018). Hence, while a qualitative design does not provide a generalisation for all, it provides a contextualised and rich understanding of the human condition or a given experience or phenomenon of interest through gaining an in-depth understanding of specific cases (Polit & Beck, 2010). As this study aims to explore the experience of living with terminal cancer, a qualitative research design was determined as the most suitable approach. Further, as the purpose of this study is to provide an in-depth insight into one's experience, namely living with terminal cancer, rather than investigating a given attribute in a larger sample, a qualitative approach was deemed appropriate (Willig, 2013).

3.4. Interpretivist research paradigm

The intellectual foundations and conceptual underpinnings of a particular research study are referred to as a research paradigm (Hua, 2015). While there is a spectrum or continuum of research paradigms which encompasses both interpretivist and positivist approaches to research (Newman et al., 1998), qualitative methodologies typically follow an interpretative standpoint that is compatible with the inductive nature of qualitative scientific research (Mangan et al., 2004). Fossey et al. (2002) posited that interpretivism places a strong emphasis on comprehending the meaning of human experiences and how this helps to explain human behaviour. According to the interpretivist paradigm, people's experiences and perceptions shape their interpretation of reality, making truth and knowledge subjective as well as historically and culturally placed (Ryan, 2018). Further, according to Eliaeson (2002) and McIntosh (1997), interpretivism refers to research methodologies that take the stance that people's understanding of reality is a social construction made by human actors, specifically ruling out the procedures of natural science. As it is concerned with the specificity of a given situation, the interpretive philosophy promotes the significant value of rich qualitative data in the pursuit of knowledge (Chowdhury, 2014). An interpretivist paradigmatic approach has been deemed appropriate for this study as it aims to explore a specific situation and to explore one's experience of living with terminal cancer and the individual meaning that each participant associates with this salient experience within their lives (Coyle & Tickoo, 2007). Based upon this interpretivist stance, and the focus on lived experience in this study, an interpretative phenomenological approach will be taken to gain rich insights into the experience of those living with terminal cancer. This methodology is informed by key concepts within the philosophy of knowledge, namely phenomenology and hermeneutics (Smith et al., 2021). These philosophical approaches will be discussed below.

3.5. Phenomenology

Phenomenology is a philosophy founded by Edmund Husserl in the early twentieth century (Moran, 2005). Husserl was considered as the founder of phenomenological perspectives in psychology (Langdridge, 2007) and the creator of the phenomenological underpinnings of psychological approaches to research (Ashworth, as cited in Smith, 2015). Phenomenology refers to "the study of human experience and the way in which things are perceived as they appear to consciousness" (Langdridge, 2007, p.10). Husserl's primary insight was that consciousness was the condition of all human experience and famously posited that to understand an experience, it was essential to "go back to the things themselves" (Husserl, 1983, p.35). Essentially, this involved investigating an experience as it appeared in consciousness (Moran, 2005).

Consistent with Cartesian Dualism, Husserl believed in the duality of mind and body and that one's mind was always conscious of, and directed towards, a phenomenon of interest, which he referred to as intentionality (McConnell-Henry et al., 2009). Intentionality was a concept which was originally created by Brentano and further developed by Husserl (Moran, 2000). Intentionality was a key aspect of consciousness, where one's orientation was directed at the object of enquiry (Zhongwei, 2014). In this way, taking a phenomenological approach to an experience involved turning one's attention towards it in an attempt to understand it (De Giovanni, 2018). For Husserl, his main focus was to find the essence or "true meaning" of an experience or phenomenon and he posited that this could be understood through a person's thoughts of their reality or lifeworld (Dowling & Cooney, 2012, p.23). Husserl coined the existential phenomenological concept of one's 'lifeworld' which incorporated all of the background understandings within one's lived experience that makes knowledge meaningful (Harrington, 2006). This concept helps one to understand lived experience through description by someone who has had the experience within their lifeworld and consciousness, which is core to descriptive phenomenology (Willis et al., 2016).

For Husserl, one's experience must be investigated from the "first-person" perspective in order to gain an understanding of the meaning of that experience in the context of one's lifeworld

(Ashworth, as cited in Smith, 2015, p.12). Further, Husserl posited that phenomenological investigation of one's lifeworld or lived experience could be achieved through "phenomenological reduction" (Husser1, 1999, p.33), also known as bracketing and epoché (Husserl, 1983; Larkin et al., 2011). Bracketing is a defining characteristic of Husserl's phenomenology, which involves the suspension of one's natural attitude or everyday experience, and all prior presumptions, experience and knowledge of a phenomenon and instead adopting a phenomenological attitude, (Drummond, 2007) which is free from all assumptions and to consciously reflect an object or experience of inquiry (Smith et al., 2021; Larkin et al., 2011).

Heidegger (1927) was a student of Husserl and he built upon Husserl's phenomenology. Heidegger rejected Husserl's concept of 'bracketing' and instead, he posited that an interpreter's prior understanding facilitated their interpretation of an experience or phenomenon (Koch, 1995). Heidegger (1927; 1996) believed that there was an interpretive aspect associated with philosophical phenomenology as one cannot engage in pure description of a phenomenon without their own bias or prejudices present (whether it be consciously or unconsciously). Hermeneutic phenomenology was developed by Heidegger to highlight the descriptive and interpretive elements involved in phenomenological analysis (Zalm & Bergum, 2000). For Heidegger (1927, p.59) "appearance" was an important aspect of hermeneutic phenomenology. This referred to the examination of something as it showed itself, which had visible meaning which was "brought to light," and also examining hidden aspects and bringing them to light to find the "hidden meaning" and uncovering how they were connected (Smith, 2022, p.19). In seeking meaning in interpretation therefore involved examining both the surface and the hidden or concealed aspects to gain a fuller understanding of a phenomenon. Heidegger's hermeneutic phenomenology differed from descriptive phenomenology as it was interpretive and focused on importance of the historical meaning and ‘pre-understanding’ that an individual associated with a phenomenon (Laverty, 2003). Pre-understanding or ‘fore-structure’ was an essential aspect of one’s being in the world, which could not be ‘bracketed’ or eliminated from one’s understanding (Koch, 1995).

In contrast to Husserlian phenomenology, the interpreter was deemed by Heidegger as being an essential part of the research in understanding of the ‘being in the world’ of the participant (McConnell-Henry et al., 2009). Heidegger contended that interpreters of a phenomenon co-created data through the use of the ‘hermeneutic circle’ (Smith et al., 2009). The hermeneutic circle is an iterative process which involves a dynamic relationship between the whole and the part of a phenomenon. In order for an interpreter to gain a deeper understanding of the whole phenomenon, it is necessary to gain a greater understanding of each part or aspect of the phenomenon and vice versa (Smith, 2007). Through repeated rounds of interpretation within the hermeneutic circle, deeper insight and understanding of the data is achieved through iterative re-contextualisation between both whole and part (Smith et al., 2021).

Gadamer built upon the insights of Heidegger in his work, *Truth and Method* (Gadamer 1975; 1989). Gadamer contended that the focus of research should be an investigation of how people interpret their lives and make meaning of their experiences (Cohen et al., 2000). From Gadamer’s (1989) perspective, the focus of hermeneutic phenomenology was to gain an insight into how individuals understand the world in which they live. Gadamer posited that understanding was an “original characteristic of the being of human life itself” (Gadamer, 1989, p.259). Similar to Heidegger, the concept of ‘fore-structure’ of understanding was significant in the hermeneutic experience for Gadamer (1989) and he contended that one’s understanding or interpretation was influenced by one’s ‘fore-structure’ or pre-understanding. Having an awareness of one’s preconceptions and an openness to “working the fore-structure” in an effort to eliminate projections of meaning onto text was essential prior to and while interpreting text (McManus Holroyd, 2007).

Gadamer (1989, p.448) further noted the importance of language in hermeneutic phenomenology and posited that “our experience of the world is bound to language.” Similar to Heidegger, he believed that language, understanding and interpretation were essential aspects of ‘being in the world’ and he perceived interpretation as a “fusion of horizons,” an interplay between an interpreter’s expectations and the meaning of the text (Laverty, 2003). He agreed with Heidegger that there was no absolute truth, but rather a new understanding of a phenomenon through the fusion of horizons (Taylor & de Vocht, 2011). He posited that interpretation was limited by the intersecting horizons of the participant and researcher (Flood, 2010). Gadamer also maintained that socio-cultural and historical context had an important influence on the meaning and interpretation of language (Dowling & Cooney, 2012).

Several distinct phenomenological research methods have been developed using descriptive and hermeneutic phenomenological approaches. Three of these key approaches to phenomenological qualitative research methods will be discussed in turn. These include Giorgi’s (1992) descriptive phenomenological approach, van Manen’s (1990) hermeneutic phenomenological approach and Smith's (1996) IPA approach. A rationale and justification for the use of IPA will follow this.

3.5.1. Descriptive Phenomenology

Giorgi (1992) developed a descriptive phenomenological method which was based on Husserl's phenomenology. Key aspects of this approach were reflective of Husserl's work on the role of consciousness, intentionality and essence as outlined above (Giorgi, 1997). It also highlighted the importance of adopting what Giorgi termed 'a descriptive attitude' where "one describes what presents itself precisely as it presents itself, neither adding nor subtracting from it" (Giorgi, 1992, p.121). This phenomenological approach was further developed into a descriptive psychological phenomenological method (Giorgi & Giorgi, as cited in Smith, 2008). This method essentially involves the key aspects of the descriptive approach to philosophical phenomenology, such as description, reduction and essence, however, it was revised to encompass the scientific nature of psychological research (Giorgi et al., as cited in Willig & Rogers, 2017). It deviates from previous phenomenological approaches as a description of a phenomenon is provided by an individual using a 'natural attitude' instead of a phenomenological attitude (Giorgi, 2009). During analysis, the researcher engages in 'scientific reduction' as opposed to 'phenomenological reduction' (Giorgi, 2009). The unified description provided by participants is separated into meaning units by the researcher and through phenomenological psychological 'scientific reduction,' the lifeworld expressions are transformed into a psychological structure which encompasses the essential features and 'psychological essences' of the description of the experience (Giorgi et al., as cited in Willig & Rogers, 2017).

The aim of this method is to create descriptive accounts from each participant and combine a commonality of experience to create a general structure of a phenomenon (Smith et al., 2021).

This approach has been critiqued by proponents of hermeneutic phenomenology, who highlight the importance of the role of context and the role of the interpretation of meaning in discovering a deeper understanding of an experience (Matua & Van Der Wal, 2015). Finlay (2009, p.11) posited that in phenomenological practice, interpretation "constitutes an inevitable and basic structure of our 'being-in-the-world.' We experience a thing as something that has already been interpreted." Hence, for proponents of hermeneutic phenomenology, interpretation is an inevitable aspect of the understanding of participants' lived experiences of a phenomenon (Langdridge, 2008). In the case of IPA, a key focus of this method is the investigation of an experience in the context of the lifeworld of an individual (Smith et al., 2021). Interpretation is an essential aspect in gaining an understanding of a participant's experience. In the interpretation of a participant's experience, researchers acknowledge their prior knowledge or experience of a phenomenon rather than 'bracket' it, and engage in reflexivity to mitigate against any potential bias (Smith et al., 2021).

3.5.2. Hermeneutic Phenomenology

Van Manen (2016; 2023) formalised Heidegger and Gadamer's approaches to phenomenology and developed a new type of hermeneutic phenomenology as an empirical research methodology and referred to this as 'phenomenology of practice' which, again, utilises both descriptive and interpretive elements. Van Manen proposed a method that is fundamentally practical and enabled non-specialists to utilise the method in a variety of contexts such as psychology, medicine and nursing (Dowling, 2007). This method is often utilised to understand the practice of professions and events that naturally occur within everyday life, rather than a single significant experience in one's life (van Manen, 2017; Errasti-Ibarrondo et al., 2018). According to van Manen (2014, p.280), phenomenology of practice is a "reflective study of pre-reflective experience" aimed to investigate what an everyday experience is like to live through. Interviews are unstructured, but the researcher is oriented towards an openness to lived experience through stories told by the participant (van Manen, 2014). The personal meanings and experiences obtained through interview texts are transformed by the researcher into disciplinary understanding (van Manen, 1997; Thomé al., 2004). Van Manen built upon Husserl's concept of intentionality in his phenomenological method, stating that all aspects of thought "imagining, perceiving, remembering" always refers to thought about something (Dowling, 2007, p.132). Van Manen (2017) posited that epoché and reduction associated with descriptive phenomenology are essential aspects of phenomenological inquiry in order to orient towards phenomenological meaning and for meaning to appear and to find the 'essence' of a phenomenon as it shows itself in consciousness. Similar to Heidegger, van Manen (1997) did not support Husserl's view on bracketing. Van Manen (1997) highlighted the importance of the use of the hermeneutic circle in terms of the dynamic interplay between part and whole and the role of the researcher in the research. Further, van Manen utilised four existentials to guide and support the process of phenomenological process of questioning, reflection and writing of phenomenological research (Dowling, 2007), namely lived space, lived time, lived body and lived human relation, which together form the lifeworld of an individual (Van Manen, 1990).

A key focus of this approach is to understand the 'essence' or key aspects of an experience and also the meaning of that experience, based on the descriptions of participants (Alhazmi & Kaufmann, 2022).

IPA draws upon the principles of hermeneutic phenomenology, such as the importance of interpretation and the use of the hermeneutic circle in understanding the lived experiences of individuals. However, as the main focus of IPA is to explore how an individual makes sense of an experience, the role of the researcher is to understand an experience from the participant's perspective (Pietkiewicz & Smith, 2014). Unlike van Manen's phenomenology of practice, the IPA researcher plays an active role in the analysis as they engage in a process of a 'double hermeneutic' (Smith et al., 2021). While hermeneutic phenomenology seeks to gain an understanding of the essential aspects of an experience and the socially constructed meanings of that experience (Matua & Van der Wal, 2015), IPA emphasises the importance of idiography also, whereby each individual's experiences of a phenomenon is examined and included in the final report. Hence, the focus is on the particular experience rather than the universal experience (Pietkiewicz & Smith, 2014).

3.5.3. Interpretative Phenomenological Analysis (IPA)

IPA was developed by Jonathan Smith for the examination of personal lived experience (Smith, 1996). The aim of IPA is to examine a participant's lived experience and how they make sense of this in the context of their social and personal world (Smith et al., 2009) and also to gain an insight into how this experience relates to their view of their world and their relationships with others (Smith & Nizza, 2022). A key focus of IPA is for a researcher to gain an insight into what it is like for someone to experience a significant personal life event such as the onset of illness (Smith et al., 2009) and to investigate the meanings that participants hold for this particular event that occurs in their life (Smith & Osborn, as cited in Smith, 2008). According to Smith and colleagues (2009, p.128) an IPA study assists a researcher “in helping to understand what it is like to have a major personal experience.” IPA also considers the research to be a dynamic process. A goal of IPA is to gain, as far as possible, an ‘insider’s perspective’ of the phenomenon under study (Conrad & Roth, 1987). However, while a researcher attempts to gain an insight into the participant’s personal world, this may not be entirely possible to achieve (Smith et al., as cited in Murray & Chamberlain, 1999). The process of understanding and interpreting an individual’s life world is influenced by the researcher’s own preconceptions, which are necessary in order to make sense of an individual’s personal and social world through a process of interpretation (Smith, 1996).

According to Smith (2004), there are three key components of IPA. It constitutes a philosophical approach, provides a framework for conducting research and describes a body of empirical studies adopting this qualitative methodology (Smith, 2004). IPA has been developed from three theoretical underpinnings, namely phenomenology and hermeneutics as outlined above, and idiography (Smith, 2017).

IPA is phenomenological in terms of the emphasis of interest being placed upon meaning of experience or a phenomenon within one’s life (Giorgi & Giorgi, 2003). Unlike descriptive phenomenology, however, IPA highlights the active role of the researcher as they attempt to interpret the personal experience of the participant (Smith, 2019). Descriptive psychological phenomenological method involves capturing the essential qualities of a specific phenomenon (Giorgi, 1997). IPA differs from this method as its purpose is to capture particular experiences as experienced by particular people rather than examining the eidetic meaning or 'essential properties' associated with a given phenomenon (Dahlberg & Dahlberg, 2020).

IPA may also be understood as having an interpretative or hermeneutic approach. Similar to hermeneutic psychological phenomenology, the hermeneutic circle is used in IPA by the researcher to gain a greater understanding and interpretation of a phenomenon, as experienced by a research participant (Smith, 2007). This begins with the researcher acknowledging their own preconceptions prior to analysis and then following the hermeneutic circle through repeated levels of interpretation to gain deeper insights into and a greater understanding of each part of the participant's experience in order to gain a more holistic understanding of the experience (Smith et al., 2021). However, it differs from hermeneutic phenomenology as both the participant and the researcher attempt to make sense of an experience (Smith & Nizza, 2022). In this way, IPA adopts a two stage process of interpretation or 'double hermeneutic' (Smith et al., 2021). As the participant attempts to make sense of their world, so too is the researcher attempting to make sense of the participant making sense of their world (Smith, 2004, p.40).

IPA is also idiographic and thus differs from both descriptive and hermeneutic phenomenology, as it acknowledges the experience of each individual in the final analysis. Idiography aims to gain an in-depth insight of a given phenomenon and provide a detailed analysis that would not be possible on aggregated data (Shinebourne, 2011). Idiography highlights the importance of an individual as a specified unit of analysis (Smith et al., 1995). The IPA methodology necessitates the construction of a detailed analysis of the personal experience of each case in order for the experience of each participant to still have a presence in the finished report and it ensures that both convergences and divergences within the study sample are included and discussed (Smith et al., 2009; 2021). An important aspect of this methodology is to produce an interpretative analysis which is reflective of the account provided by each participant (Smith, 2017).

IPA may also be considered as being inductive, and interrogative (Smith, 2004). IPA utilises an inductive approach to data analysis. The flexible nature of IPA allows topics that were unexpected to emerge within the data during the analysis phase. Therefore, there are no specific hypotheses established by researchers in advance when conducting an IPA study (Smith, 2004). Similarly, the interrogative nature of this approach enables researchers to discuss their findings relative to existing literature, frameworks or models (Brocki & Wearden, 2006). Smith (1996) highlighted the similarity between IPA and social cognition as they both aim to identify the relationship between how people think, what they say and how they act (Eatough & Smith, as cited in Willig & Rogers, 2017). IPA researchers aim to maintain flexibility within their methods and avoid preconceived ideas when coming to the analysis in order to provide the rich data that qualitative research has the potential to capture (Brocki & Wearden, 2006).

IPA was first used as a distinctive research method in psychology in the mid-1990s (Shinebourne, 2011). Since then, it has become an increasingly popular methodology in health psychology (Pietkiewicz & Smith, 2014) and has more recently been utilised in diverse disciplines such as education, sport and exercise, dance and business (Noon, 2018; Smith & Sparkes, 2016; Milne & Neely, 2022; Tan et al., 2023). IPA is particularly suited to the investigation of health and illness, as it provides an insight into what it means for participants to experience illness and how they make sense of this phenomenon in the context of their lives (Smith, 1996). Participants are understood to be sense-making individuals who engage in self-reflection in an effort to interpret how they engage with the world (Smith & Nizza, 2022). As participants reflect on the significance of what has happened to them, they attempt to find meaning in their illness, identity and life (Smith, 2019).

3.6. IPA in the context of this Research

The aim of this study is to explore the experience of living with terminal cancer from the perspective of terminal cancer patients themselves. IPA was deemed the most appropriate method of data collection and analysis due to its focus on the lived experience of a given phenomenon, namely living with terminal cancer, and how individuals make sense of that experience within the context of their lives. IPA aims to capture a rich and detailed analysis of a phenomenon as it is experienced by an individual, which includes convergences and divergences of experience across cases, unlike Giorgi’s (1997) approach as previously described, which focuses on developing accounts based on the similarity of experience to build an ’eidetic picture’ or essence of an experience to provide a general structure of a phenomenon (Smith et al., 2021). Further, the result of an IPA study is an interpretive commentary, which is idiographic and includes participants extracts (Smith & Nizza, 2022). This idiographic feature of IPA is relevant to the current study as it ensures that the wide scope and depth of participants’ own personal experiences and acknowledges how contextual factors around them may affect their individual experience. Further, the idiographic features of the IPA method ensure that individual narratives are included in the finished report and the convergences and divergences of participant experiences are included and explored. This is in line with the aim of this study which is to understand the experience from the perspective of each of the participants themselves in the context of their own lives.

In the case of Giorgi's phenomenological psychology, the outcome is in the form of a third person narrative derived from the descriptive accounts of participants to describe the universal essence of a phenomenon (Smith et al., 2021; Matua & Van Der Val, 2015). While van Manen's method as previously described, includes both phenomenology and hermeneutics (Finlay, 2014), its focus is on everyday events in an individual's experience (van Manen, 2017), whereas IPA focuses on a significant or particular personal experience, event or relationship (Smith et al., 2009). The IPA method differs from descriptive phenomenology in its structured approach to analysis, consisting of a series of analytic steps or processes (Smith, 2019). It differs from other qualitative methods due to the iterative nature of the analysis and not only its use of the hermeneutic circle, but also the emphasis placed on the double hermeneutic, that is the researcher making sense of the participant's sense making of their world (Smith, 2019). The results are presented as a concise and compelling narrative, which are structured into group experiential themes and subthemes. Hence, it was deemed by the researcher that IPA was the most appropriate method for the purpose of the study.

IPA provides a dual emphasis on the importance of the description and interpretation of the personal meaning associated with a particularly significant experience such as illness (Smith et al., 2018). IPA is both hermeneutic and idiographic in its approach to analysis. It is hermeneutic through its focus on individuals' interpretations of their experiences and the meaning which an experience of a phenomenon has for an individual and it is idiographic in that it emphasises the unique personal experience of a phenomenon (Smith et al., 2009). The IPA approach investigates individual experiences, how individuals interpret these experiences and identifies similarities or differences among each unique experience (Smith et al., 2009). IPA will ensure that the voice of individuals with terminal cancer is appropriately captured in the research and ensures an in-depth and rich approach to data analysis that is appropriate for the key concerns of this group (Smith et al., 2009). Open-ended questions are a key feature of this approach, allowing the participant to speak openly about their experience of the phenomenon (Smith, 2008). The interview schedule utilised within this research focuses on encompassing the experience of living with terminal cancer and how an individual makes sense of that experience. Psychological, social and spiritual concerns are explored within the context of that experience.

The authors of IPA posit that, while it is vitally important for a researcher not to impose any of their own preconceptions or biases onto the research, they also acknowledge that having some prior knowledge may be useful (Smith & Nizza, 2022). For example, conducting a literature review of existing studies on the topic of interest may provide a researcher with an opportunity to look more closely into particular areas of interest and to refine their own research question. Also, the findings of a literature review may highlight an area that could benefit from a deeper investigation of a person's personal experience into it and what it means to an individual in the context of their own world, hence it can provide the rationale for an IPA study (Smith & Nizza, 2022). Further, it is acknowledged that some IPA researchers are “insiders” who may have some experience of the phenomenon being investigated (Smith & Nizza, 2022, p.12). While being an ‘insider’ of an experience may be beneficial as it can help the researcher to understand the context of an experience and to build up a rapport with participants, it is also important for the researcher to be reflexive prior to and during the research process and to acknowledge their own biases as they adopt a phenomenological attitude of investigating the world of their participants (Smith & Nizza, 2022). In the context of this empirical study, the IPA method acknowledges the potential benefit of prior knowledge and experience in the research area which may potentially help the researcher to gain deeper insight into the phenomenon and to better understand what it means for an individual to live with terminal cancer.

3.7. Reflexivity and Researcher Positioning

Researcher positioning refers to the position that a researcher has taken with a specific research study (Manohar et al., 2017). Relevant factors that influence the position of a researcher include personal factors such as gender, age, race and sexual orientation, as well as other factors such as one’s personal beliefs, experiences and biases (Berger, 2015). The position of the researcher may influence the findings of one’s research as the researcher plays an active role in shaping the researcher-participant relationship, and their disposition or role may influence how they ask specific questions or how they interpret the data collected, hence shaping the findings in an alternate way (Kacen & Chaiten, 2006). According to Sevin-Baden and Major (2013), researchers may demonstrate an awareness of positionality by defining their location in the context of the research, understanding their stance in relation to participants and being aware of their role within the research process.

The acknowledgement of researcher positioning and reflexivity has become an essential aspect of the qualitative research process as it aids one’s understanding of the phenomenon being studied (Watt, 2007). According to Ben-Ari and Enosh (2011), reflexivity refers to a purposeful awareness on the researcher's part that includes both a contemplative disposition or state of mind, and deliberate behaviour with active engagement intended to recognise disparities and generate knowledge. Reflexivity is multifaceted by nature and requires that attention is paid to personal and contextual factors as well as methodological issues which may influence the study that is being conducted by the researcher (Olmos-Vega et al., 2023). Qualitative researchers may demonstrate reflexivity through questioning their own view of reality, questioning their own relationship with the context of their research and considering what their perception of ‘valuable research’ is (Cassell et al., 2017). As researchers demonstrate reflexivity by describing the relationship that co-exists between themselves and the participants within their research, their findings become more credible (Dodgson, 2019).

In this study, the researcher demonstrated an awareness of researcher positioning and reflexivity as she completed reflexive practices throughout each stage of the research and following each interview to enhance the rigour of the study. From the outset, the researcher acknowledged her position in relation to the topic being explored. The researcher is a white female in her late 40s who lives in Dublin, Ireland. She does not consider herself as religious, despite having a Roman Catholic background and upbringing. Rather, she considers herself as being spiritual and engages in spiritual practice as she lives her life. The researcher has previously cared for family members who lived with terminal cancer. The researcher acknowledged her own potential bias due to her spiritual beliefs and her experiences as an informal carer and has engaged in reflective practice throughout the PhD process to mitigate against this. **An extended reflexivity statement has been included in the appendices.**

The researcher recruited all participants herself and had disclosed to all participants that she has had previous experience as a caregiver to terminal cancer patients and this experience instilled the passion in her to complete this PhD study. Each participant was contacted by phone initially to speak to the researcher about the study and to confirm that they would be eligible to participate. This gave the researcher the opportunity to build rapport with potential participants in advance of the research interview taking place, making it easier for participants to feel comfortable and at ease while discussing a sensitive topic. Despite this, the researcher acknowledged her role within the research and acted as a facilitator in the interviews where participants were given the opportunity to share their own stories based on their lived experiences. Reflexive notes were taken during interviews about points that participants made and these were considered during the transcription and analysis process. Further, the researcher completed reflections at the end of each interview noting her initial observations, key points that she felt were important to consider in each participant case and how she felt before, during and after each interview.

The researcher mitigated against potential bias arising from her own position by writing a personal reflection prior to the study. This involved acknowledging any potential bias which may have arisen from the researcher's previous role as an informal caregiver. Second, in line with the IPA method, a semi-structured interview guide which only included non-leading open-ended questions was constructed. This guide was peer reviewed by the supervision team and received approval from the Research Ethics Committee of the University. Third, at each stage of analysis, meetings were held with the supervision team to ensure that the analysis was conducted by the researcher in a completely inductive manner. Fourth, during analysis, both convergences and divergences among participants were investigated by the researcher to gain a more holistic view of the experience and to mitigate against confirmation bias. Finally, the analysis and research findings were peer reviewed by the supervision team to protect against potential bias.

3.8. Conclusion

This chapter outlined the methodology adopted in this research project. The qualitative research approach and interpretivist paradigmatic stance have been discussed and justified. An outline of the phenomenological approach to this research project was then outlined. Further, an overview of the specific methodology being utilised in this study, IPA was provided. Lastly, researcher positioning and reflexivity was acknowledged.

Chapter Four:
Empirical Methods

“Information is not knowledge. The only source of knowledge is experience. You need experience to gain wisdom”

Albert Einstein.

Chapter Four

Empirical Methods

4.1. Introduction

This chapter outlines the empirical methods and the research procedure followed throughout this research study. The research design is outlined and justified, followed by a comprehensive description of the sampling and participant recruitment process utilised by the researcher. Further, the data collection procedure is described and the risk management protocol is explained in detail. Finally, data management and analysis will be discussed by the researcher.

4.2. Research Design

In determining the type of research design suitable for this study, several factors were considered in line with those outlined by Flick and colleagues (2004). These included but were not limited to: the aims of the study, the central research questions, the researcher's level of control, ethical considerations and the temporal resources available to the researcher. This study has a cross-sectional qualitative research design. Cross-sectional studies are carried out at a specific point in time (Levin, 2006). Cross-sectional studies are particularly useful in the context of health research as they can be useful for exploring one's experience of illness (Pandis, 2014). Qualitative cross-sectional research designs are effective in allowing participants to elaborate on their own narratives based on their lived experiences (Spector, 2019). Further, Spector (2019) has highlighted that cross-sectional research designs are most useful in situations where one is conducting exploratory research and the timeframe is unknown. This was important to consider for this study as participants were terminally ill with a short prognosis and some participants had already passed away before the research was completed. Hence, a qualitative cross-sectional design was deemed as being most appropriate by the researcher to obtain quality and information rich data with this particular sample.

4.3. Sampling and Recruitment

4.3.1. Inclusion criteria

The participant profile for the patient group was English-speaking adults over 18 years of age with the capacity to give informed consent and who have received a cancer diagnosis that is terminal (with a prognosis of up to 12 months). While some participants were initially diagnosed with metastatic cancer, each of these patients had been given a prognosis of less than 12 months, indicating that they were in the terminal phase of their disease. Participants were not receiving curative treatment at the time of the interview, but some participants may have been receiving palliative care for symptom management and quality of life purposes only. This prognosis was self-reported by patients when they expressed an interest in participating in this study. Following initial emails from potential participants who expressed an interest in taking part in the study, the researcher contacted each individual by phone to ascertain whether they had received a terminal cancer diagnosis or a diagnosis of advanced cancer with a prognosis of up to 12 months from their oncology consultant. Ten individuals confirmed that they had received this diagnosis, while thirteen individuals reported that they had not and were excluded.

4.3.2. Sampling

IPA is most suited to a small number of participants, ideally between five and ten, in order for the researcher to closely examine each individual case (Smith et al., 2009). This small sample size facilitates the researcher in gaining a detailed understanding of each participant's unique psychological experience of a phenomenon (Smith & Sparkes, 2016), rather than striving to provide generalisability across a population (Vasileiou et al., 2018). Ten individuals living with terminal cancer (n=10) were interviewed, as is commensurate with IPA research of this nature and was highlighted as the optimal number of participants for a PhD project by the seminal authors of the method in the recent edition of their book and in personal communication with them (Smith et al. 2009; Smith et al., 2021).

4.3.3. Recruitment

Participants in this study were recruited through national and local cancer centres including but not limited to, Hope Cancer Support Centre, ARC, Irish Cancer Society, Daffodil Nurses, East Galway and Midlands Cancer Support. While it had been initially proposed to target clinical sites such as hospitals and hospices for recruitment purposes, this was not possible due to the COVID-19 pandemic as hospitals and clinical sites were not supporting external research at this time and only essential visitors were allowed to enter the premises. Several cancer supportive services and charities with Public and Patient Involvement (PPI) groups were contacted and asked to share the recruitment poster drafted and designed by the researcher (including Breakthrough Cancer Research among others). Further, the researcher created a

Facebook and Twitter account for this study and sponsored online posts on social media channels including Facebook, Twitter and Instagram for participant recruitment purposes. Additionally, a recruitment poster was shared widely by other researchers, the newsletter of cancer centres (specifically Breakthrough Cancer Research) and DCU social media accounts across different social media platforms to ensure as many potential participants as possible could be reached from several different communication mediums. This poster (see Appendix C) offered information about the study and provided the contact details for the researcher as a point of contact should potential participants have wished to obtain further information or to express an interest to take part in the research.

PPI groups associated with cancer charities and organisations across Ireland played a significant part within the recruitment strategy for this study. Members of PPI groups were contacted with the recruitment poster for several reasons. Firstly, when designing the research poster aimed at recruiting potential participants for this study, members of the Breakthrough Cancer Research PPI group offered feedback on the first draft of this poster. These members offered advice on the type of language that would be most suitable to use and attract potential participants for this study. This was particularly useful in the context of this project due to the perceived stigma associated with the term 'terminal cancer' as many individuals would prefer to say that they are living with 'advanced cancer with a prognosis of less than 12 months' than to take part in a study focusing on terminal cancer patients only. This was reflected on the poster for recruitment purposes. Additionally, this redrafted poster was shared with members of several PPI groups across the country for recruitment purposes. Some eligible members offered to participate in this study while others passed on the information to family members, friends or other acquaintances who would have met the inclusion criteria.

While several potential participants came forward and demonstrated an interest in taking part in the study, many potential participants were ineligible (N = 13) as they did not meet the inclusion criteria stating that they must have had terminal cancer with a prognosis of less than 12 months, rather than a diagnosis of advanced or high-grade cancer with no indication of their prognosis. Many of these participants were not specifically told that they had terminal cancer but were informed that they had advanced cancer with a poor prognosis and were therefore, deemed ineligible to participate in this study. Other potential participants were not informed of their prognosis by their oncology consultant and were still undergoing curative treatment and were also deemed ineligible to participate in this study. Ten participants with terminal cancer (N = 10) who met the inclusion criteria volunteered to take part in this study (see Table 4.1).

Table 4.1.

Participant characteristics

Name (Pseudonym)	Age	Gender	Primary Cancer Type	Time since initial diagnosis	Type of initial diagnosis	Time since terminal diagnosis	Marital Status
Layla	42	Female	Ovarian Cancer	13 years	Metastatic	10 years	Single
Evelyn	60	Female	Metastatic Breast Cancer	17 years	Metastatic	5 years	Separated
Kiera	50	Female	Multiple Melanoma	16 years	Metastatic	6 years	Married
Danielle	56	Female	Colon Cancer	5 years	Metastatic	1 year	Single
Diana	80	Female	Bowel Cancer	3 years	Terminal	3 years	Widowed
Adele	58	Female	Breast Cancer	5 years	Terminal	5 years	Married

Table 4.1.

Participant characteristics

Name (Pseudonym)	Age	Gender	Primary Cancer Type	Time since initial diagnosis	Type of initial diagnosis	Time since terminal diagnosis	Marital Status
Joanne	59	Female	Lymphoma	7 years	Metastatic	4 years	Separated
Ben	46	Male	Colorectal Cancer	11 years	Metastatic	2 years	Separated
Darragh	58	Male	Sarcoma	15 years	Metastatic	1.5 years	Married
Linda	64	Female	Breast Cancer	6 months	Terminal	6 months	Separated

4.4. Data Collection

4.4.1. Semi-structured interviews

Semi-structured interviews were used to examine the phenomenon of living with terminal cancer from the perspective of patients themselves living with terminal cancer. Interviews have been identified as a social encounter where knowledge is co-created through a reflexive joint action in which the interviewee and interviewer participate, according to the interpretivist research approach (Taylor, 2002). Miller (1999) posited that the researcher can acquire a thorough grasp of the narratives of participants in the context of their own lifeworlds, including the meanings they attribute to specific phenomena, by using semi-structured interviews. Additionally, semi-structured interviews have been identified as the most suitable method of data collection associated with IPA as they enable researchers to gain an in-depth understanding of each participant case (Brocki & Wearden, 2006). Hence, one-to-one semi-structured interviews were used as the primary method of data collection as they minimise any potential participant distress and discomfort, while also ensuring that participants can tell their own stories (Willig & Rogers, 2017).

4.4.2. Interview guide

The interview guide was constructed in line with the IPA methodology, which involved developing a ‘logical’ sequence of questions, which initially identified broad areas of the experience, and which gradually moved towards asking about the participants’ meaning making of specific aspects or “funnelling” of the experience (Smith et al., 2021, p.57). Beginning with broad and open questions enabled participants to become comfortable with speaking about themselves and their experience. Each interview began with the descriptive question of ‘tell me about yourself.' As participants became more comfortable with speaking, they were asked open-ended questions about their experience of living with terminal cancer centered around four central questions: their experience of living with dying, the aspects of their lives that were most important to them, their sense of meaning and/or purpose in life and their wishes for the future. Prompts such as 'can you tell me more about that?' were used to gain additional insight into participants' experiences and meaning making. Probes such as 'what do you mean by that?' and 'how did that make you feel?' were also used to elicit participants' thoughts and feelings about their experiences (Smith et al., 2021).

The interview guide questions were developed in line with IPA's phenomenological, hermeneutic and idiographic commitment, which enabled a deep and detailed exploration of the lived experience of terminal cancer and a rich insight into the meaning that this experience had for each participant in the context of their lives. The researcher drew upon phenomenological, hermeneutic or interpretative phenomenological analysis peer-reviewed empirical studies which focused specifically on the lived experience of advanced cancer patients approaching end of life or terminal cancer patients. Additionally, the questions specified in the NCCP Model of Care for Psycho-Oncology Distress Assessment tool were also referred to in the development of the interview guide for this study (Greally et al., 2020). Examples of these questions included 'how are you coping?' 'what is your biggest concern?' 'what is important to you at the moment? and 'is there anyone (friends/family/cancer support services) that you can call on for support?'. Due to difficulties in finding appropriate people living with terminal cancer to pilot the interview guide, the researcher piloted the questions in a role play with her supervision team who had significant experience in interviewing vulnerable populations.

Questions about participants' experience of living with dying were informed by questions posed by previous authors, such as Coyle (2006); Ryan (2005); Bertero et al., (2008); Kyota and Kanda (2019); and Levy and Cartwright (2015). These studies were relevant given their focus upon living while dying in the context of terminal illness or advanced cancer. Similarly, questions about the aspects of participants' lives that were most important to them were informed by similar questions posed by Ryan (2005); Fan and Eiser (2012); Esteves et al., (2015); Harrop (2017); and Krigel et al., (2014). Further questions relating to meaning-making and purpose in life were informed by similar questions posed by Harrop (2017); Eustache et al., (2014); Tamura et al., (2006); and Schapmire et al., (2012). Lastly, questions regarding participants' wishes for the future and end of life were informed by Huang et al., (2018); Schapmire et al., (2012); Adler et al., (2019); and Roulston et al., (2018). The interview guide used has been included in the appendices (See Appendix D). Additionally, some demographic questions were asked by the researcher following each interview regarding their age, type of cancer, marital status, nature of their disease and time since their diagnosis (See Appendix E).

4.4.3. Interview setting

Due to the ongoing governmental restrictions that were imposed due to COVID-19 and the potentially vulnerable health status of the participants required for this study, the researcher conducted the interviews both in-person and remotely via the telecommunications application Zoom. It is important to acknowledge that, in situations where the COVID-19 restrictions were lifted, or in a phase whereby people outside of one household were allowed to meet, participants were given the choice of a location convenient to them for the interview, such as their home, place of treatment or a public place where the participant may be comfortable but also suitable for a recorded interview (e.g. a public library, quiet café etc). Participants' homes were included as potential locations for this research, as research suggests that the home environment facilitates a greater degree of participant comfort and a more 'giving' relationship between researcher and participant (Sivell et al., 2015). However, in situations where the country was in a full lockdown during the COVID-19 pandemic (whereby travel was restricted within 5km for essential purposes only), all interviews were conducted via Zoom. This platform was recommended to the researcher by the DCU Research Ethics Committee and the supervising researchers as it supported end-to-end encryption. Only one participant completed their interview in-person (N = 1). This took place in a hotel at the participant's request, while the other participants all chose to complete their interview remotely due to concerns about their health and the COVID-19 pandemic restrictions at the time (N = 9).

4.4.4. Data collection procedure

For those who were interviewed online, prior to the interview using the Zoom application, participants were all asked for their email addresses by the researcher. Once their email address was provided, participants were sent a plain language statement and a consent form by email (see Appendix F) in advance of the interview and were each required to return a copy of the form with their e-signature or typed signature (in the case of emailed consent forms), indicating their consent to be interviewed online. The consent form contained questions with 'yes' or 'no' boxes, and participants were required to tick these in response to the questions asked. Participants were all made aware that the consent forms would be stored in a separate location to the interview data. A risk management protocol for socially distanced interviews was drafted by the researcher, following published public health guidelines at the time (see Appendix G). This protocol was designed to protect and maximise the wellbeing of both the participants and the researcher involved in the data collection process.

Before each interview, all participants had another opportunity to read the plain language statement (see Appendix H). Participants were also verbally reminded of the content within this form and were asked to verbally give informed consent again. The length of the interviews ranged from 50 to 109 minutes (mean interview length: 76 mins). All interviews were recorded through a voice recording application on an iPhone and the files were uploaded directly to a secure Google Drive account that was password protected. As soon as possible after completing the interview, the data gathered was transcribed verbatim by the researcher. No participants withdrew from the study following the completion of their interview; however, should a participant have decided to withdraw from the study before the completion of the PhD thesis, they were advised that their data would be withdrawn and deleted.

On the plain language statement, information relating to relevant counselling services was made available to participants, along with contact details for the researcher. Additionally, a check-in system for participants was provided after the interview for those who decided to opt in. This check-in system was only utilised if participants wished to be contacted following the interview and were happy to receive a follow-up call to see how they were (following their consent and the provision of relevant contact details). In total, 3 participants opted in and were contacted following the interview by the researcher.

The researcher made participants aware of the potential dissemination routes on the plain language statement. It was stated in the plain language statement that the present research would form the basis of a PhD thesis and that the findings would be disseminated in published journal articles, at academic conferences and via Breakthrough Cancer Research's dissemination channels (such as social media accounts and newsletters). Participants were informed at the beginning of the interviews that they may request a one-page summary of the findings of the study and that these may be requested from the researcher. Each participant was enthusiastic about the findings of the study and will be contacted following the completion and final submission of the PhD thesis with a one-page summary of the findings.

4.5. Data Analysis

Following transcription of the audio recordings, the data was transferred into the analysis template made by the researcher to facilitate the analysis of the transcripts according to the IPA method (see Appendix I). This template was used to facilitate analysis of the data and a sample of an analysed patient transcript has been included in the appendices (see Appendix J). The interpretative phenomenological analysis method, as described in the previous chapter, was employed (Smith et al., 2021). The steps followed within this process are outlined in Table 4.2 and described below.

Table 4.2.

Interpretative phenomenological analysis (IPA) process

Step Number	Step Description
1	Reading and re-reading the first case.
2	Making exploratory notes on the content, semantics and language within the first case.
3	Constructing experiential statements related to the experience of the participant in each case.
4	Searching for and identifying connections that exist across experiential statements.
5	Naming the personal experiential themes (PETs).
6	Repeating the individual analysis process across the other cases.
7	Explore convergences and divergences within the PETs to develop group experiential themes (GETs) across cases.

At the beginning of the data analysis process, researchers are required to focus on the first case specifically and to engage in reading and re-reading this case. When commencing the analysis stage of this project, the researcher focused explicitly on the case of 'Layla.' While the researcher followed the steps outlined by Smith and colleagues (2021) and engaged in reading and re-reading the transcript to familiarise herself with the case, it is noted that she also completed full (and manual) transcription of the data herself and was therefore, already very familiar with the case and data collected.

Following familiarising herself with the data, the researcher made exploratory notes on the first case. These exploratory notes were based on the content of the interviews as well as relevant semantics and language. For example, in the case of 'Layla,' exploratory notes included 'happier now,''life is better now' and '[cancer] is the only real negative thing in my life'.

Once the exploratory notes for the first case were completed, the researcher focused upon constructing experiential statements. Experiential statements differ from the exploratory notes as they are more interpretative in nature and focus upon the experience of participants as interpreted by the researcher. In the case of 'Layla,' some sample experiential statements include 'finding happiness in new lifestyle' and 'cancer becoming a part of everyday life.'

While still focusing on the first case specifically, the researcher focused upon identifying connections that existed across the experiential statements that were constructed in the former step. The connections were identified from a thematically related perspective as well as a temporal perspective across one's cancer trajectory, in line with their individual narrative. An example of a connection that was identified by the researcher in the case of 'Layla' included 'appreciating life,' 'finding happiness in her new lifestyle' and 'gaining a perspective of gratitude.'

Following the creation of connections among the experiential statements identified by the researcher, these connections were named. These connections were termed by Smith and colleagues (2021) as personal experiential themes (PETs) as they reflect the themes that were identified within individual cases. Some examples of PETs identified in the case of ‘Layla’ include ‘reframing the cancer experience’ and ‘(un)relating with others.’

Following the completion of the first five steps for the first case, these steps are repeated for each of the other cases within the study. These were completed for each of the ten cases included within this study as part of the data analysis process.

Once the first five steps were repeated across all ten cases, the final stage of the analysis required the researcher to explore convergences and divergences that existed between cases. This involved the researcher compiling the PETs for each case and exploring the similarities between cases to create group experiential themes (GETs). Additionally, divergences or differences between cases were also explored in line with the idiographic nature of the IPA approach. Some of these divergences included that ‘Linda’ felt lonely and isolated, and did not actively seek out connections with other people following her diagnosis resulting in a lack of meaningful relationships in her life, whereas all other participants proactively constructed, maintained and valued the relationships they had in their lives. For example, ‘Darragh’ proactively constructed an individual support system for himself and highlighted that these relationships were ‘essential’ for his emotional wellbeing. Each of the convergences and divergences that were developed into GETs will be discussed in further detail in chapter five.

Data analysis was discussed and checked with the supervision team at each stage of the process. All identifiable data was removed and replaced during the first stage of analysis to ensure anonymity and confidentiality for all participants. Further, during the analytic process, the researcher noted language that specifically conveyed rich descriptions of and meaningful insights into participants' experiences. This included the use of metaphors and allusions which helped to provide a greater understanding of participants' own interpretation and sense making of their unique experiences. This also included utterances and short passages used by participants which offered deeper insight into an individual's and in some cases, group experiences of a phenomenon. These are what Smith (2011) termed 'gems.' According to Smith (2011), gems play a pivotal role in experiential qualitative psychology as they illuminate particular aspects or nuances of a phenomenon and provide a greater understanding of an experience.

In line with the IPA method (Smith et al., 2021), the results were presented as a narrative account, which began with a short summary of the research findings. Each group experiential theme (GET) which was presented, began with a brief summary of what was found. Sub-themes were outlined and participants' experiences were presented in the following format; introduction of each participant who addressed the sub-theme, followed by a relevant participant quote, and followed further by an analytic and interpretative commentary on how the quote illustrated the experiential theme (Smith & Nizza, 2022). Convergences and divergences among participant experiences were also highlighted.

4.6. Ethical Considerations

4.6.1. Ethical Approval

Ethical approval was granted from DCU Research Ethics Committee in 2021 following the completion of the ethics approval form and the associated DPIA (data protection impact assessment) for health research form (Ref: DCUREC/2021/102, see Appendix K).

4.6.2. Risk and Risk Management

The level of risk of this study was deemed moderate and it was subject to a full DCU Research Ethics Committee review due to potential vulnerabilities relating to the target samples of terminal cancer patients. This research project, however, did not place participants at any greater risk than they would experience during everyday life, given their terminal disease. The topic of terminal illness is one inevitably discussed and faced in everyday life by these individuals and is also frequently covered in the media. As such, this is a topic that participants would have been likely to encounter in their everyday lives given that they are/were currently living through the experience of terminal cancer. Nonetheless, it was possible that participating in this interview could have highlighted this topic to them and may have made them distressed. A number of measures were taken to attempt to deal with this appropriately. Participants were fully informed about the purpose and content of the interview in advance of their participation. The plain language statement stated that factors relating to participants' experiences of terminal cancer were being investigated and that this would be a central topic of conversation. Despite this, psychological, social and physical risks among others were considered by the researcher and mitigated against where possible.

4.6.2.1. Psychological Risks

As outlined above, the risk associated with participation in this study was moderate as it was possible that participants may have experienced stress or anxiety as a result of their involvement. Stress or anxiety may have been caused by thinking about their situation (living with terminal cancer), while anxiety might have been a result of participants fearing that death may be impending on them or a loved one in the near future. Although death and illness are inevitable parts of life for any human being and is a commonly discussed topic within the media, there was a risk of participants feeling stressed or anxious about a possible fear or worry regarding the prospect of impending death as a result of their participation in this study. In order to address this risk, the protocol was drafted and was followed and relevant information regarding support services was offered to participants. Contact details for relevant national counselling services were included in the debrief section should participants have felt the need to contact them. Contact details of the principal and supervisory researchers were also included, with participants encouraged to make contact with any questions that they might have had about the study. In addition, participants were informed that they were free to withdraw from the study at any stage prior to completing their interview, should they wish to have done so.

4.6.2.2. Social Risks

A possible social risk could have been that potential participants felt obliged to take part in this research if they had been contacted by a gatekeeper who was responsible for their care or the care of a loved one. Participants, however, were informed from the outset that their participation in the study was completely voluntary and they were free to withdraw from the study at any stage prior to completing their interview should they wish to have done so. Further, gatekeepers were not involved within the recruitment process to minimise any potential obligation that the participants may have felt in this situation.

4.6.2.3. Physical, Legal or Economic Risks

No participants were placed at any risk of physical harm as a result of participation in this research. A check-in system for participants after the interview was provided. Due to GDPR, this check-in system was only to be utilised if participants wished to be contacted following their interview and were happy to receive a follow-up call to see how they were (following their consent and the provision of relevant contact details). In addition, there were no legal or economic risks associated with completion of this study.

4.6.2.4. Specific Risks to Researcher and Risk Management Procedures to Minimise these Risks

It was possible that entering participants' homes and meeting participants in-person could have posed a risk to the principal researcher. A robust check-in and check-out system has been indicated in the protocol, the PhD researcher checked in on the SafeZone app before any in-person interviews took place in order to mitigate risk. The researcher checked-in and shared her location with the DCU security team before the interview commenced. The check-in timer was set for the duration of the interview and the researcher checked-out when the interview was completed. In the event that the researcher did not check-out, the SafeZone application would have alerted DCU security services and a response team would have been able to check the location of the researcher. This protocol was used for offsite locations such as interviews in a patient's home or in public places and was designed in-line with DCU lone and out of hours working policy. Also, the researcher did not provide her personal contact details to potential participants outside of her DCU email address.

It is also acknowledged that the content of the interviews could have been potentially distressing for the researcher. The PhD researcher was conscious of the possibility of experiencing emotional distress due to the sensitive nature of the research topic being discussed. The researcher had experience in discussing sensitive topics such as death and euthanasia from completing two previous research projects in this area, one of which has already been published (Hayden & Dunne, 2020). As part of these studies, the researcher had explicit conversations about these topics and hence, was already familiar and comfortable with these topics. Should the need have arisen, the researcher had maintained a pre-existing working relationship with an independent therapist who could have facilitated with supervision, should it have been required. Further, the researcher had attended regular therapy herself during the course of this project for her own health and wellbeing purposes. Additionally, the principal supervisor was available for debrief immediately after each interview and was in a position to suggest onward referral if he felt that this was required. Additionally, the researcher had experience in conducting qualitative interviews with these groups from two prior studies that she had completed and was skilled in sensitive interviewing techniques which minimised any potential risks.

4.6.3. Data Handling

Due to the nature of qualitative interviews, the data collected in this project could not be completely anonymous (i.e. to the researcher). Participants were informed on the plain language statement that their data would remain strictly confidential, and that all necessary steps would be taken to de-identify the transcript, removing all identifiable features from it following transcription of the audio recordings by the researcher (e.g. replacing names with pseudonyms, removing location names, etc.). This ensured that those who participated in the interviews were not identifiable based on the transcript excerpts that would be included in the written thesis or publications arising from this research. In addition, only the principal researcher and the supervisory researchers had access to the data. The data has been stored securely and will remain confidential. Participants were made aware in the plain language statement that in rare circumstances, the principal researcher may be asked to provide information about specific individual participants that partake in this research under law.

Data was collected through an audio device (iPhone) that recorded all of the interviews. Following each interview, the audio file was saved to a password protected DCU Google Drive account and then deleted from the device as soon as possible. The individuals with access to the data were the principal researcher (audio and de-identified transcript) and the supervising researchers (audio and de-identified transcript). Participants were also informed that the examiners of this thesis would also have access to some of the data collected, (de-identified transcript only on request).

The consent forms and other hard copy documentation have been stored securely in a locked cabinet in the School of Psychology on Dublin City University Campus. The consent forms required participants to sign their name and they were asked only to select ‘yes’ or ‘no’ in response to each question. Only the principal researcher has had access to the consent forms and hard copy data until the study has concluded. At this point, the data transfer process to the supervisor will be completed.

The audio data and de-identified transcripts that are stored on Google Drive will be retained for a period of five years following completion of the project. This data can be accessed with the correct username and password only. The soft-copy of the audio data stored on the principal researcher’s password-protected google drive account will be completely removed from the account once the final thesis has been submitted. The rationale for keeping the audio files is due to the benefit of being able to check the meaning of particular sentences when doing the analysis, for example in relation to tone and inflection.

The hard copies of the consent forms have been kept in a locked cabinet in the School of Psychology on Dublin City University Campus. Only the principal researcher and the supervising researchers have had access to this locked cabinet. When the project is complete, interview scheduling information, including telephone numbers, participants’ addresses, and email addresses will be deleted by the principal researcher. All hard copy and soft-copy data will be transferred to the primary supervisor who will store the data securely (on his password protected and encrypted computer for audio files and transcripts and in a locked filing cabinet in the case of consent forms) and he will be responsible for data disposal/destruction (deletion of computer files and shredding of consent forms) after five years.

4.7. Conclusion

This chapter outlined the research procedure followed in this study. The research design has been discussed and the participant recruitment process has been explained in detail. Participant demographic details have been presented and the data collection process has been described and explained. Further, the steps of the IPA analysis process have been outlined by the researcher. Lastly, ethical considerations including the risk management protocol and data management procedures have been acknowledged and considered in light of the research that was undertaken.

Chapter Five:
Results

"If I take death into my life, acknowledge it, and face it squarely, I will free myself from the anxiety of death and the pettiness of life – and only then will I be free to become myself"

Martin Heidegger.

Chapter Five

Results

5.1. Introduction

This chapter will outline the findings of this study following analysis. Utilising an IPA approach, six group experiential themes (GETs) were identified by the researcher. These include *Recovering Control in Uncertain Times, Gaining an Increased Awareness of Time, Negotiating a Changing Identity, Finding Comfort Through Connection, Navigating the Social World and Journeying with Hope.* These GETs and their associated sub-themes are presented below in table 5.1.

Table 5.1.
Group experiential themes and sub-themes

Group Experiential Themes (GETs)	Sub-themes
Recovering control in uncertain times: *'[It's] getting used to the idea that I can live with this [cancer] in my life'*	● Spiralling out of control: '*You're just caught in this whirlwind'* ● Regaining a sense of control: *'Never forget that this is your disease […] it's a very important thing that I think also fits into this ownership of managing my own situation'* ● Learning to live with uncertainty: *'That whirlwind just keeps going around except I've more of a handle on it'*
Gaining an increased awareness of time: *'All of a sudden, you're told 'the clock is ticking'*	● Feeling Existential angst: '*It [Cancer] haunts me most of every day'* ● Valuing Time as currency: '*I value my time more than I value anything else'* ● Living on borrowed time: '*Of course, nobody knows, but 2010 was my expiry date, so I'm definitely living on borrowed time now'* ● Leaving a legacy: *'I'd like to be remembered as somebody who died well, having lived well'*
Negotiating a changing identity: *'All of a sudden, I'm a patient with a chart'*	● Becoming the terminal cancer patient: *'It's very hard to adjust to seeing yourself as a cancer patient'* ● Shifting between past and present identities: *'You have this weird dichotomy, […] there's no handbook that tells me how to manage that disjoint'* ● Re-defining oneself: *'I've become stronger and more confident in who I am'*
Finding comfort through connection: *'I don't have to worry about it […], I'll go through the pearly gate'*	● Connecting with self: '*I just go with the flow. I listen to my body and my body tells me what to do'*

	● Forging a connection with God or a higher power: ‘*I consider God a friend in my life, […] he has helped me and supported me’* ● Feeling connected to nature: ‘*It’s almost a bit of a meditation for me’*
Navigating the social world: *‘The support that I have is incredible, and is critically important to my well-being emotionally’*	● Feeling detached from others: *‘You learn not to open up and talk to people about this stuff’* ● Relating to other terminal cancer patients: ‘*They’re the only ones who really get it’* ● Cultivating meaningful relationships: *‘My family, they’re my reason to get up every morning’*
Journeying with hope: ‘*Life is all about hope’*	● Losing hope: ‘*There is no hope, is there?’* ● Finding hope: ‘*If you don’t have hope, where is your future?’* ● Living with hope: *‘Hope never abandons you, you abandon it’*

5.2. Recovering Control in Uncertain Times: ***‘[It’s] getting used to the idea that I can live with this [cancer] in my life’***

Participants recall how they experienced losing control over their lives after receiving their terminal cancer diagnosis and felt great uncertainty and worry over their future. This feeling of *Spiralling Out of Control* over their lives in terms of their health, their care and their future had a significantly negative affect on their wellbeing. They experienced a significant sense of vulnerability and distress as they relinquished control over their health care to medical professions, due to their own lack of knowledge about their disease. They lived with great uncertainty about their future, over which they believed they had no control. Participants recall how when they started *Regaining a Sense of Control* over their lives and began to adjust to living life with terminal cancer, they felt the need to take ownership of their disease and manage their own lives. They learned to look after themselves more, to educate themselves about their disease and to take ownership over their own health and care, which in turn, helped them to live with the uncertainty of their future with more ease and less worry. This had a positive impact on their emotional wellbeing and helped them to live life feeling more empowered and in control of their lives. Participants speak about *Learning to Live with Uncertainty* by changing their perspective on how they live life. By adopting a positive mindset towards living life and by focussing on living each day instead of dying, they live more fully and meaningfully with less worry about the uncertainty of their future.

5.2.1. Spiralling out of control: 'You're just caught in this whirlwind'

Participants in this study recall having a lack of control within their own lives once they received their terminal cancer diagnosis. After receiving the news that their cancer was terminal, several participants experienced the feeling of a lack of control over their health and had significant worry about the uncertainty of their future.

Evelyn describes how she felt completely overwhelmed by the experience of living with terminal cancer and could not make sense of this phase of her life, describing it metaphorically as a 'whirlwind;'

> 'I suppose in the few years, it's just been…for me, I see it as a whirlwind. You know, back then, you know when you get the diagnosis, you're just caught in this whirlwind of

> everything…your hospital appointments, scans blood, tests and trying to make sense of everything.’ (Evelyn)

This participant describes the experience of being diagnosed with terminal cancer as a ‘whirlwind’ as she found it difficult to gain control over and to find balance within her life. Besides living with the numerous practical aspects of advanced disease such as hospital appointments, scans and tests, this participant perceives that her life spiralled out of control following her diagnosis as she became engulfed in trying to psychologically and emotionally come to terms with her diagnosis and the uncertainty of her life ahead. The use of the whirlwind metaphor provides a valuable insight into how overwhelmed and distressed this participant felt following her terminal diagnosis. The use of the phrase ‘whirlwind’ suggests that she felt unable to gain control over the reality and uncertainty of being a terminal patient and what that meant for her physically and emotionally.

Similarly, Adele recounts having a complete lack of control over her life following her terminal diagnosis;

> ‘All of a sudden you're thrown into this world of the unknown, and of course, there’s going to be emotions you haven’t ever experienced before, and you're not going to understand everything that's going on in your head.’ (Adele)

Adele suddenly found herself in a new world of uncertainty that was completely unknown to her. The use of the metaphor of being thrown into a ‘world of the unknown’ in a sudden manner to which she was a stranger, provides an insight into the significant emotional difficulty that she experienced in coming to terms with a completely new and uncertain situation in life that was outside of her control, causing her to feel a sense of unbelonging. She depicts that this experience was difficult to make sense of as she had no frame of reference in terms of how to understand, process or control the complex emotions that she was experiencing at this time.

Similarly, Linda recalls her distress over the lack of control that she experienced;

> ‘I was told ‘you have stage four.’ And to have to face the reality, because it was laid on the table there in front of me, that it was progressive. There was no treatment, I mean, I could engage with treatments that might slow it up, maybe. But ultimately, it was an inevitability that it was going to kill me sooner or later, and they just couldn't put an absolute timescale on that. But at the same time, it was made very clear to me that we were talking sooner rather than later, if you know what I mean. So, yeah, to be honest, that's incredibly devastating. It really just pulls your whole world down around your ears to be fair. […] The big difference with the kind of cancer diagnosis I've got, is it really doesn't matter what I do, there is absolutely nothing I can do to change the outcome. […] But there's nothing I can do to deal with this. Because there is nothing, it can't be fixed. And that in itself is quite difficult to cope with. Because I've lived my life fixing things, not just for myself, but for everybody around me. So, then all of a sudden, I'm presented with a scenario where there isn't any fixing. And that’s quite hard, that’s quite hard you know.’ (Linda)

For Linda, finding herself in a situation where she had no control over her life or how long she might live was ‘incredibly devastating.’ The use of the phrase ‘it really pulls your whole world down around your ears’ indicates the depth of emotional distress that she experienced following her diagnosis. Feeling in control had been an important aspect of how Linda had previously lived her life; being the ‘fixer’ with the ability to influence outcomes. In this situation where the outcome would remain the same irrespective of her attempts to influence it otherwise, she felt powerless and completely unable to control the uncertain length and quality of her life. This complete lack of control that she was experiencing for the first time in her life negatively impacted her psychological wellbeing and contributed significantly to her struggle in making sense of and coming to terms with her terminal diagnosis and poor prognosis.

Joanne also describes the lack of control that she felt over her health;

> ‘…it’s like you’re throwing yourself at the mercy of somebody else. And that you have lost control of your own situation. And now you're handing it over to the hands of somebody else. And they weren't sharing all of the information with you. And you were feeling very vulnerable.’ (Joanne)

Joanne’s lack of knowledge and information regarding her health and terminal disease status led her to feeling a sense of vulnerability and need to surrender control of her health care decisions to professionals. This handing over of control over her health and her care to professionals highlights her own perceived inability to be an active participant in making decisions regarding her health with clinicians. The lack of knowledge and information about this disease stage indicates the power imbalance in her communication with healthcare professionals. This imbalance caused ambivalence for Joanne, and influenced how she communicated with her oncologist and other medical professionals.

In summary, following a terminal cancer diagnosis, participants felt a loss of control over their health, their care and their future. They experienced vulnerability in handing over their care to professionals, due to their own lack of knowledge about their disease. They lived with great uncertainty about their future, over which they perceived they had no control. This negatively affected their wellbeing and was a significant cause of psychological distress for participants at this point in their lives.

5.2.2. Regaining a sense of control: 'Never forget that this is your disease […] it's a very important thing that I think also fits into this ownership of managing my own situation'

Several participants recall how they felt that they needed to take ownership of their disease and manage their own situation. They learned to adapt to living with terminal illness and they began to look after themselves more and took ownership over their own care. Additionally, they attempted to regain some level of control within their own lives.

Darragh describes how he regained control of his life while living with terminal cancer;

> 'This is your disease. Never forget that this is your disease. You never leave your consultant's room, unless you have asked all the questions you want to ask. You make

> sure you arm yourself with knowledge. Don't let anybody push you or pull you in one direction. ‘This is your disease,’ that just stuck in my head. That expression is really, really important, but it's a very important thing that I think will also fit into this ownership of managing my own situation.’ […] I had to build that support system, which was a really, really interesting thing to do. And in a weird way, it's possible that that's the best way to do it. Because I have built a bespoke system that works for me as an individual, as opposed to an off the shelf one size fits all for people, which may not necessarily be the case […] And these are support systems that are there if you need to, and you can pick and mix, and you can build it, you can build a support structure for yourself. And that's actually really an important thing. A little lightbulb moment for me now, is that the support system that I have built, I've built to my own specifications, and my own needs.’ (Darragh)

Darragh recognises the importance of informing oneself about the reality of living with terminal cancer. He posits that taking ownership of his terminal disease has enabled him to take control of his life and to manage the uncertainty of his healthcare. He uses the metaphor of arming himself with knowledge to indicate the importance of educating oneself about the disease in order to regain control and to make informed healthcare decisions. This has allowed him to make informed decisions about his own life and to maintain a sense of control over the uncertainty within his life. He has proactively built a ‘bespoke’ support system to his ‘own specification’ as opposed to an ‘off the shelf one size fits all’ system that suits his own unique needs within his life. This has enabled him to live his life, trusting in the support that he has built up around him.

Similarly, Layla talks about how she regained control of her life;

> ‘I think that the turning point for me [was] where it made me think that these guys [doctors] don't know everything, like you can't take everything that they say as being the only answer. You have to be your own advocate, you have to make sure that you’ve read around everything, and you are confident in what they're telling you. […] I guess I've learned a lot about myself over the time. I’ve had to learn to be a really good advocate for myself, so I've learned to stand up for myself, to question doctors and that’s not always easy to do. I always try to keep on top of what's going on research wise.’ (Layla)

Layla has taken ownership and gained control over her life by educating herself about her terminal disease and finding the confidence to question the perceived authority of medical professionals. Through gaining knowledge about her disease, she has grown in confidence to become her own advocate. Hence, she controls her situation by becoming an active participant in decision making with healthcare professionals regarding her health care and treatment.

Alternatively, Danielle speaks about her approach to regaining control;

> ‘[The cancer survivorship course] deals with various aspects, emotional and physical, like the practicalities, the importance of exercise, a healthy diet, it teaches coping strategies for stress or upset or whatever. […] Don’t just sit there, you have to help yourself, you have to put in some effort yourself. My attitude is that you can’t totally rely on medical teams as a medicine. They do their best, but they need your input as well. […] You have

> to learn to practice what they call the ‘survive and thrive’ world. It’s self-compassion. A lot of the time, you have to put yourself first. That sounds very selfish, but you’re not. You need to look after yourself as well. You can't expect everyone to do everything for you. It's too easy to fall into that, particularly if you do have enough people surrounding you to do that. But you really need to remain independent as well. So, you feel like you're participating, that you're doing something and you’re helping yourself. And don’t refuse help if you’re offered it. By that same token, don't be afraid to ask for help, even if it's not being offered.’ (Danielle).

Danielle has learned how to manage living with the uncertainty of her life and to take control of her situation by taking part in a ‘survive and thrive’ course offered by a national cancer charity. While attending this course, she learned about different strategies for living with her stage of cancer. She highlights the importance of educating oneself about the practical aspects of living with terminal disease, as well as knowing when to ask for help from others, and also managing self-care. As she has adapted to living with the uncertainty of her illness, as she has begun to take control of her life. She has gained an understanding of her own capabilities and has accepted herself the way she is. This self-acceptance and focus on oneself encourages self-compassion gives her a sense of wellbeing.

Correspondingly, Ben recalls how he regained control of his life;

> ‘There was at one stage a programme, I actually done it, it was a mojo programme. That’s actually stopped now, it was for men with depression. It was based around men

> with depression. I would have been a person who wouldn't have looked for anything to be honest, this was actually put on my lap. I wouldn't have been the person who would have went looking for it. Men don't do these types of things, but when I done the programme then, my life changed actually after I'd done the programme. I learned a lot of tools on how to control my mental health through that programme and still to this day it pays off for me. I use the tools that I had learned from that on a daily basis to maintain my mental health. And my mental health now, despite everything that I'm going through, I've never been stronger mentally ever in my life than I am now. But I wouldn't be looking for services, I wouldn't be the type of person that would have done that type of thing.' (Ben)

For Ben, attending a cancer care support group which was aimed specifically at men was a pivotal point in taking back control of his life as he lived with terminal disease. He had never considered himself previously as someone who would attend such a programme and had the perception these programmes would generally not be attended by men. However, by overcoming this aspect of himself where he would be passive about his health, his attendance at the male support group provided him with the necessary skills to take control over his mental health. Ben has learned that from listening to the experiences of others and learning about coping tools and strategies, that he can live his life well. Through gaining an understanding of how to cope psychologically and about the importance of gaining mental health, he found ways to regain control and to live his life with a greater sense of wellbeing, despite living with the uncertainty of terminal illness.

Evelyn speaks about her experience of regaining control of her life;

> ‘I wanted to be independent. […] I did, with the help of my family, move out independently on my own. With palliative care helping me, a social worker, it was discussed that it was in my best interest and of the whole family and I got help with that and so that was a move in the positive. […] I have to look after me, and that in turn helps them help me, you know. And it’s helping us live as many things as normal as we can. You know, if I focus on what I have to do to make my day best for me, then it rubs off on everyone that I deal with through the day.’ (Evelyn)

For Evelyn, having independence has been a priority while living with terminal cancer. Through engaging with the palliative care team and social worker, she has been assisted in finding ways to gain independence and take control of her life. She has learned to take control of her own life with the support of healthcare professionals, and has been able to maintain her independence through learning about the importance of engaging in self-care and managing her own health. As she has adapted to the process of looking after herself, she also gets support from others too and this has helped her to live life with an increased sense of wellbeing. She consciously seeks to maximise her own wellbeing each day, and this has contributed to how she lives with the uncertainty of terminal illness. This adapted way of living has not only benefited the participant herself, but also benefits those around her and maximises everyone’s quality of life.

In summary, as participants live with terminal disease, they have taken ownership of their situation and regained a sense of control over their lives. They have achieved this through educating themselves about their illness and learning ways to manage their care.

5.2.3. Learning to live with uncertainty: ‘That whirlwind just keeps going around except I’ve more of a handle on it’

As participants regained some sense of control over their own lives, they have learned to live with the uncertainty of their terminal illness and the lack of normality that they had previously experienced. As they adapted to their ‘new normal’ and living with their terminal illness, the sense of uncertainty has become less intimidating, and they have learned to live with their terminal disease.

Darragh describes how he has learned to live with the uncertainty of terminal cancer;

> ‘[I’ve had] to re-frame how I live with this disease. So, I accept that I am chronically ill, I have a chronic, life-threatening illness that *is* going to kill me at some point. But I can't let that limit how I live. Because if you did that, as I said, you'd just curl up under the table and not bother, you’d just turn off the lights and off you go.’ (Darragh)

Darragh has made the conscious decision to ‘re-frame’ how he lives with terminal disease. He has changed his perspective from dying of terminal cancer to living with the disease and has decided not to allow his condition to limit how he lived his life. In doing this, he has gained acceptance of his illness and of his own mortality and understands that this inevitability is not something that he can allow to act as a roadblock in terms of his life course. Through shifting his perspective from dying to living with terminal cancer, Darragh can continue to live his life more fully, rather than retreating away from the world, ‘turn off the lights’ and giving up on life.

Similarly, Joanne talks about how she has learned to live with the uncertainty of terminal cancer;

> ‘So, I suppose the thing is that you have to, you can decide with this illness, you can decide to be dying every day, or you can decide to live every day. […] You can allow yourself to become fearful of things. And it can also be the thing that prevents you from doing something that you enjoy. And you know, if you're going to go, you’re going to go. So instead of spending your time thinking, well if I do that it might make me sick and then I could die, but I could die anyway.’ (Joanne)

Joanne has decided to live with the uncertainty of terminal illness by adopting a conscious mindset of living life every day instead of having a mindset of ‘dying every day.’ Choosing to live life fully each day has allowed her to learn to live without fear and to engage in enjoyable activities. In this way, she can live with meaning and enjoy each day and not fear what the future holds for her.

In a similar way, Ben describes how he has learned to live with the uncertainty of terminal cancer;

> ‘When I first did get diagnosed, I did cry. Now, it's a part of my life now. It's just there. It [cancer] doesn't faze me. The last time I got it [cancer], I was diagnosed with terminal cancer. I just have to continue living my life, I’m here ‘til the day I go and I’m not just going to roll over and play dead because I have cancer. I’ve made so many memories over the last four years, this is my third battle in four years. And I’ve made so many memories over those four years. That’s because of my mental health. Just get up and get on with it and enjoy your life as best you can. I don’t like to see it as the end, I don’t look at it as the end. It’s opened my eyes to what life is really about.’ (Ben)

Although Ben struggled initially with his diagnosis, he has since consciously decided that he still has a life to live, and he wishes to live life to the best of his ability with this terminal disease. Through adopting this perspective, he lives with the intention that cancer will not negatively impact his experience of life, and his mindset is focused on living life as fully as he can. As he chooses to take a positive approach to living his life each day, this has helped him to move beyond the suffering that he had initially experienced after his terminal diagnosis and allows him to live a full and meaningful life, despite the uncertainty surrounding his terminal condition.

In a similar way to Ben, Adele describes how she has learned to live with the uncertainty of terminal illness;

> ‘I think now it is being happy and finding a place in my head where cancer is part of my life. But that quality of life, getting used to the idea that I can live with this in my life, and still smile and be happy and enjoy the things that happen.’ (Adele)

For Adele, choosing to be happy and to enjoy life is now a priority. She fully accepts that while living with the reality of terminal cancer is a part of her life experience, she has adopted the mindset that it will not consume her. By adopting this perspective, she has been able to put her terminal disease to the back of her mind and secure a better quality of life for herself. As her terminal disease has become a less prominent part of her life, she lives with a sense of wellbeing.

Similarly, Danielle describes how she has learned to live with the uncertainty of her illness;

> ‘I can either be miserable or get on with this and say, ‘I'm going to do my best to survive as long as I can.’ […] I’m reminded of that Hebrew prayer, I don’t know it in Hebrew, but basically in English it means ‘man makes plans and God laughs.’ And these last three to three and a half years have really brought that through […], that one is just so true for me. It really and truly is. You have to learn to yield a little bit and change your expectations, change your perspective. […] If there’s something you’re concerned about and you can change it, or you can actually do something about it, that’s fine. If there’s not, try not to worry. Some people might say I’ve a simplistic attitude, I don’t care. It works for me.’ (Danielle)

Danielle has consciously decided to change her perspective and expectations of her life as she lives with the uncertainty of her health and her future. Despite not being able to pursue her former plans, she has learned to yield to changes in her life and make the best of any situation that is in her path. She has taken control of whichever aspects of life that she can take control of and has accepted that there are others that are outside of her control at the moment. She uses the phrase ‘man makes plans and God laughs’ to suggest how she learned the value of having plans, but recognises the need to be flexible enough to change them and to surrender control of those plans, when necessary. She has decided to take this perspective as she chooses not to dwell on the things that she cannot control and to live with that simple attitude towards living life. This way of living life has positively impacted her wellbeing and how she continues to live with her terminal illness.

Similarly, Evelyn describes how she has learned to live with the uncertainty of terminal cancer;

> ‘That whirlwind just keeps going around except I’ve a more of a handle on it. I’m able to slow it down, dip in and out of it, and deal with bits of it here and there.’ (Evelyn)

Evelyn had previously described her experience of living with terminal cancer as a ‘whirlwind,’ however, as she has learned to cope with the uncertainty that she previously experienced, she has become more capable of gaining control over the whirlwind that she once experienced to be overwhelming. This metaphor of having a ‘handle’ on the ‘whirlwind’ when referring to her cancer journey explains how she has learned to deal with it and control it in her own unique way, when she was ready. This has enabled her to feel more in control and feel able to live with the uncertainty of her life while living with her terminal illness.

In summary, as participants learned to live with the uncertainty of their future, they recovered a sense of control over their own lives. Through changing their perspective of how they lived with their illness and by adopting a positive mindset of living life instead of dying, participants learned how to control those aspects of life that they could control and to live with less worry about what they could not control. This helped them to live with less worry about the uncertainty of their future.

In conclusion, after receiving a terminal cancer diagnosis, participants experienced feeling a lack of control over their lives and an overwhelming sense of fear and worry over the uncertainty of their future, which caused intense emotional distress. As participants lived with their terminal disease, they regained control over their lives through educating themselves about their illness and their care. They have changed their perspective on life and have decided to consciously live in the present moment rather than worrying about the future. This change in mindset has helped them to adapt to living life in a positive way and regain a sense of control to live more fully with their terminal illness, despite their knowledge of their finitude.

5.3. Gaining an Increased Awareness of Time: *'All of a sudden, you're told 'the clock is ticking'*

Following their terminal cancer diagnosis, each of the participants speak to varying degrees about their increased awareness of the passage of time. Each participant describes how this increased consciousness of time they have left to live has been a cause of existential distress and death anxiety. In many cases, *Feeling Existential Angst and* intense feelings of worry and despair have been experienced during the night-time hours, when participants lie alone with their thoughts in the silence and the darkness of the night. While participants describe times of deep despair and intense negative emotions, they also speak about how they are conscious to make the most of the time that they have left to live. Several participants speak about *Valuing Time as a Currency*, spending their valuable time on meaningful activities with those who matter most to them and living with purpose. A few participants talk about the importance of creating enjoyable 'moments' of time to remember in the future. Several participants describe how each day that they continue to live is perceived as a gift and a blessing, which they value and appreciate immensely. They describe how they now perceive themselves as *Living on Borrowed Time* and they use this time as an opportunity to engage in self-reflection and personal growth and they view life from a different perspective than before. Each participant speaks about how they wish to be remembered after they have died. Some participants talk about *Leaving a Legacy* of being a good parent and friend, others wish to leave a legacy of inspiration and some wish to leave a legacy of hope. Leaving a legacy helps participants to live with peace in the knowledge that they have lived a life of value and meaning.

5.3.1. Feeling Existential angst: 'It [Cancer] haunts me most of every day'

All of the participants describe how, since their terminal cancer diagnosis, they have lived and continue to live with periods of struggle with death anxiety. While this was experienced most intensely in the period immediately after their initial diagnosis, they continue to experience existential distress caused by the knowledge of their impending death. Several participants describe how they have become overwhelmingly conscious of the passage of time since their diagnosis and have become acutely aware about how long they might have left to live. For participants, this conscious awareness of time means periods of intense worry and concern regarding the longevity and meaningful nature of their lives. Each of the participants has experienced some level of death anxiety since their terminal diagnosis and has struggled to live with this aspect of their life.

Linda describes her continued intense feeling of existential distress;

> ‘As human beings, even if you didn't have a cancer diagnosis, you do not know when you're going to die, or how you're going to die necessarily. So, in some senses, nobody knows that. Once you're given a [terminal] diagnosis, that all changes, because all of a sudden, you're told the clock is ticking.’ (Linda)

Linda views her diagnosis as the certainty of her death approaching. This diagnosis signals the end of her life as she knows it. She has become aware that a time limit has now been placed on the length of her life and she is struggling to come to terms with this. She uses the metaphor of a clock ticking to describe how much more aware of the passing of time that she has become. The ticking of the clock is a stark reminder that the length of her life is finite and will come to an end prematurely, due to her terminal diagnosis.

Linda further describes how she struggles to live with existential distress;

> ‘I wake up literally every day. [My awareness of death] is in my mind, and on my mind. It haunts me most of the day, and I go to bed with it, you know what I mean, to get up another day. I personally find it quite bleak. I mean, it's kind of like I’m existing, you have no choice.’ (Linda)

Linda describes how her awareness of death is something that ‘haunts’ her throughout the day. She finds her future to be ‘bleak’ and believes that she has no other option but to continue to exist while living with a sense of existential dread, where the meaning within her life has been diminished as she feels trapped within the disease. She experiences significant distress caused by the knowledge of her impending death. Her use of the word ‘haunting’ evokes a feeling of being scared of something that’s present and ominous, but not necessarily tangible. It provides an insight into how utterly emotionally distressing this experience is for her.

In a similar way, Darragh describes how he experiences existential distress;

> ‘Everybody else thinks you look fantastic…But at the same time, there’s a loud ticking noise going on in the back of your head…[Having] this voice in the back of your head, you’re really sensitive to time passing by. […] And there is always, always, always on a day-to-day basis, there is always this little voice at the back of your head that says it's going to kill you. It's always there, it whispers quietly in the back of your head.’ (Darragh)

Darragh also uses the metaphor of a ticking clock to describe his increased awareness of the passage of time and his finitude. Despite being told that he looks well by others around him, this participant remains acutely aware of the fact that there is a ‘loud ticking noise’ and a ‘little voice’ that ‘whispers quietly’ in the back of his head which continually remind him of his mortality. He is ever present to the existential dread of living with this disease and to the reality of his mortality. The metaphor of a ‘loud ticking noise’ indicates the helplessness of this participant in terms of his finitude. The disconnect between how he outwardly appears to the world and the reality of the impact of the disease on his inner world, knowing that this disease will cause his untimely death, adds to the sense of isolation in this situation that this participant experiences.

Darragh further describes the constant reminder of his mortality he has each time that he attends a scan;

> ‘There's absolutely no way of knowing what's going to happen. […] So, your mortality kind of becomes, you become a little bit more aware of your mortality every time there’s scans and meeting your oncologist comes around, because in a five-minute conversation, he could change your life completely.’ (Darragh)

Before attending each scan, Darragh ruminates over the fact that the results could potentially indicate how much time he has left to live. The experience of each scan makes him increasingly aware of his finitude and reminds him of his vulnerability due to living with terminal cancer.

Kiera describes how she struggles with existential distress and death anxiety even on positive occasions;

> ‘There was a lot of stuff that was very emotional, even Mother’s Day, we went out for a meal, my birthday. I had a complete meltdown on my birthday, much to everybody’s surprise. But I was convinced that it was my last birthday.’ (Kiera)

Kiera has the heightened awareness that every significant date or point in her life may potentially be the last one that she could experience. This struggle to experience normal everyday events in the knowledge of her finitude has a significantly negative impact on her emotional wellbeing as she has what she describes as a ‘complete meltdown’ on her birthday, thinking that it might be her final one.

Several participants describe how, in their struggle to make sense of their terminal diagnosis, they become more aware of their deeper emotions when they are alone in the silence of the night-time hours. It is during these hours of darkness that a hyper-awareness of time left arises and where they experience their darkest and more complex emotions. For some participants this experience is found to be particularly distressing.

Danielle describes her emotional distress in the silence and darkness of the night-time;

> ‘Like, I’ve had times, particularly it seems I wake up in the dead of night, at around three or half three and it’s pitch dark and silent. At least where I live it’s silent, and that's kind

> of, I find if I'm going to feel low, that’s when it tends to hit me. That hour of the night. And I’ll have a little cry for myself, and a little whinge, and I’ll feel sorry for myself and then I’ll go back to sleep.’ (Danielle)

For Danielle, her deeper emotions arise during the night time hours, when it is dark and silent while she is feeling ‘low.’ Her use of the phrase ‘dead of night’ portrays a heightened reminder of death. It is at this time that her worries and deep buried emotions about her mortality arise, and she becomes hyper-aware of her time left. In this darkness and silence while being alone, she allows herself to feel her more challenging emotions and to relieve them before returning to sleep.

Night-time hours are also found to be particularly distressing in a physical way for Adele;

> ‘The night-time stretches on and on and on. So, I did lie in bed, and I just tossed and turned, and I tried to turn my head off. Even if I dozed off, within seconds, I was waking up like I was drowning. So, my brain wasn't even allowing me to switch off. That was very visceral.’ (Adele)

The distress experienced by Adele is due to an overwhelming sense of fear and worry about her awareness of death and her finitude, which arise in her mind at night when she tries to sleep. In the times where she does manage to fall asleep, she finds herself waking abruptly while experiencing an out of body sensation of being submerged in water and drowning. The use of the metaphor of having the feeling of drowning is very insightful, as it gives voice to the depth of this participant's fears and existential worries about her terminal condition.

For Darragh, the hours of night are a time when he is confronted with his fear of death, he describes this;

> 'There are times when you really do feel really, really dark, you really do find yourself, you know, the lights have gone out, and the room's gotten cold. And you know, you can feel fingers, cold fingers on your shoulder. And it's, it's emotionally really, really, really stressful. And it's very easy to drift into that mindset, and it's difficult to get out of.' (Darragh)

Night-time hours are when Darragh faces his most difficult and complex emotions about death and how much time he has left to live. During times of facing his deepest fears, he struggles to remove himself from negative thinking. His use of language of lights going out, the sense of coldness in the room around him and how he felt 'cold fingers' being placed on his shoulder provide an insight into how he feels within close reach of death at this time. The use of the term 'cold fingers' evokes an image of a dead hand or the grim reaper standing beside him, placing a hand on his shoulder, indicating that death is near.

In summary, participants live with death anxiety and experience significant existential distress caused by the knowledge of their impending death. For participants, they experience existential distress due to the loss in the longevity and meaningful nature of their lives. In several cases, the night-time hours are a time when emotional distress is experienced most significantly, as participants become more aware of their emotions and have time to reflect on them in the silence and darkness alone. The use of metaphors such as drowning, and the cold finger placed on the shoulder in the darkness provide insights into the depth of thought and reflection on their fears and worries about death.

5.3.2. Valuing Time as currency: 'I value my time more than I value anything else'

While participants live with significant periods of struggle with existential distress, worry and anxiety, where in many cases, several of them view their lives as a 'ticking clock' they also speak about how they have also become more aware of the value of their time. Each of the participants perceive it as something of great importance and many value their time now as a currency, which they want to spend wisely.

Layla describes how she has begun to value her time above everything else in life;

> 'I value my time more than I value anything else. I don't care how much money I have or material things I have or any of that stuff. Like, if I've got time to enjoy life and do the things that I want to do, then that's the most important thing to me.' (Layla)

Layla values the time that she has left above all else. Money and possessions no longer hold the same meaning for her. Time is now perceived as her most valued commodity and she spends her precious and limited time left finding joy through engaging in meaningful activities.

Adele also speaks how she prioritises different aspects of her life based on the limited time that she has left to live;

> ‘For me, it's not seeking out the best holiday or the most expensive car, or to have flash clothes. It's just being able to get up every day on your own, have your breakfast, go for a walk, those kind of things. For me, it's just about being able to get about my little life, my little quiet life.’ (Adele)

Adele’s perspective of life has now changed, and she prioritises her time experiencing everyday things rather than objective material things that she would have once sought. She enjoys spending her time living a simple existence. She no longer prioritises material items, but values her time spent living a peaceful life immensely more.

Similarly, Darragh talks about how he creates moments of time to enjoy in his life;

> ‘I do try and find moments of peace and happiness. For the most part, I’m reasonably content, it must be said […]. And every now and again you just sit out [in garden] and you just feel a sense of peace and I think in terms of what's important to me, is trying to find opportunities for those moments. But I enjoy life, I do enjoy life, I enjoy cooking. […] Taking the dogs out for a walk is something I enjoy doing.’ (Darragh)

For Darragh, time is measured in meaningful moments, as he lives purposefully, spending time engaging in activities that bring him peace and happiness each day. By consciously creating moments of enjoyment each day, he ensures that he finds regular periods of peace and joy for himself.

Ben also chooses to spend his valuable time creating moments of happiness in life. He describes this;

> 'A lot of people worry about stupid material things in life. Things that don't matter. Material things don't matter to me in life, it's about enjoying it. I'd rather spend a half an hour on the green talking to a stranger and having a giggle than to be offered a free car. Because it's a memory. For me, life is *now* about creating memories.' (Ben)

Having been faced with his finitude and with the awareness of his limited life expectancy, Ben now values his time over material belongings and prioritises finding time to enjoy himself while creating positive memories. He prefers to spend meaningful moments of enjoyment with others over being offered material items. Through seeking out valuable moments of joy and opportunities to create happy memories with others, he has found new meaning, positivity, and peace in his life.

For Joanne, the recognition of the transience of life is important. She describes this;

> 'We're only passing through here for a short period of time. And when we're here, we should do the very best that we can. […] Just live a simple life. And you know, whatever

> you have, if you can share what you have, do that and show a little bit of kindness to somebody every day.' (Joanne)

Joanne recognises the briefness of time available to her and the uncertainty of her future. This realisation has influenced her to consider how her positivity and enjoyment in the simplicity of life and in the time she has left to live her life could help both herself and others in a meaningful way.

Diana speaks about how she prioritises spending time in familial roles each day;

> 'As I'm living at the moment, I'm living a good life, I'm very content […] Right now, I have to just be who I am, for as long as it takes. And that's it. My purpose is to be still here as a mother or grandmother and try and be the best I can for as long as I can. And just be with my family. That's it.' (Diana)

For Diana, spending time with those closest to her fills her with a sense of contentment and happiness, where she can feel at ease and in peace. Spending her valuable time with family members and continuing to live life with meaning and purpose provides her with fulfilment and with reduced worry for the future.

In summary, while participants live with continued and extended periods of feeling existential distress where their worries and concerns of their finitude can become completely overwhelming, they also experience periods where they have a different perspective of time, and view it differently. While they are acutely aware of the passage of time and reflect on their finitude, they use time differently and use it as currency. This currency enables participants to spend their valuable time engaging in meaningful activities, with those who matter most and live with purpose, which help to alleviate some of the existential distress that they experience.

5.3.3. Living on borrowed time: 'Of course, nobody knows, but 2010 was my expiry date, so I'm definitely living on borrowed time now'

For those participants that have outlived their prognosis, living well on borrowed time is very important. While they each had received a prognosis of less than a year, they have lived beyond that date. In these cases, participants were faced with their fear of death. However, since they have lived well beyond their predicted life expectancy or 'expiry date,' they are continually acutely aware of the uncertainty of the time left to live life, they value the gift of time they continue to be given each day, and view life from a different perspective than before. Each day that they continue to live is perceived as a gift and a blessing, which they value and appreciate immensely. Several of these participants also perceive their time while living beyond their prognosis as an opportunity to engage in reflection and personal growth that they may not otherwise have engaged in. These participants' gratitude for life and unexpected additional time to live significantly influences how they live their lives with meaning and purpose, despite their terminal disease and knowledge that their days of life are numbered.

Ben considers his life now as a blessing, he describes this;

> ‘Every day I feel blessed when I wake up to continue on with life. I appreciate the time I have here, nothing is taken for granted. I suppose what I’m trying to say is I don’t take anything for granted anymore.’ (Ben)

Ben appreciates the gift of each new day, which he views as a ‘blessing’ to him. He no longer takes any aspect of his life for granted and he makes the most of the time that he has left, knowing that it may come to an end unexpectedly and at any time.

Similarly, Danielle speaks about how she has an increased appreciation of life;

> ‘You learn to appreciate life. You learn to appreciate what you have instead of complaining about what you don’t have. You really get to appreciate your family and friends. And even just nature and looking around you and hearing the birds singing and watching the babies playing. It’s funny ‘cause I think we just live such busy, busy lives, we don’t take time to stop and smell the roses and appreciate it. Just to sit for five or ten minutes. It’s really worth it. Just the simple pleasures of life. All the bodily functions you take for granted when you’re well and they all go skew ways when you’re not well. It’s a whole different ball game. And I’m not going to go into it, but let’s just say I won't take them for granted again.’ (Danielle)

Danielle has become more conscious of spending time purposefully and with meaning. She highlights how the challenges that she experienced with her health and her lack of control over her bodily functions have helped her to appreciate the days of good health that she has, which she will never take for granted again. Further, she now values each additional day that she is given to live her life in a meaningful way, spending her valuable time with family and friends, and has learned to slow down and to spend her time appreciating the beauty of the world around her.

Similarly, Joanne speaks about having an increased appreciation of life and spending time in different ways than before;

> ‘I suppose there was a learning in the whole journey. And like that, if it did anything, it made me stand back and you know, appreciate life and not take life for granted […] like that I live a much simpler life now and I suppose when I retired, I didn't think I could afford to live but then you cut your cloth to suit whatever and I can afford to live and like that, I don't have to be going out.’ (Joanne)

Joanne views life differently than before and values her ‘journey’ of self-reflection, and growth and the time she has spent learning more about herself. She learned not to take anything for granted and to live life in a simpler and more meaningful way.

Layla views herself as living on ‘borrowed time’ as she had far outlived her prognosis, she describes this;

> ‘Of course, nobody knows, but 2010 was my expiry date, so I'm definitely living on borrowed time now. So, I just have to keep living my life. […] Every decision I made,

> everything that happened led me to where I am now, so I wouldn't change that. Yeah, it's been a ride and, in some ways, I'm really quite, it sounds weird, but grateful to the situation that I've found myself in, because like I say, it brought things to a head and brought me to a place where I'm safe and happy and I'm living a much fuller life. And I can thank cancer for that really.' (Layla)

This additional and unexpected time that Layla has had to live life has enabled her to live with renewed purpose and meaning and gratitude for the personal growth she experiences while living beyond her prognosis. She also feels appreciative of the experience and grateful for the opportunity for reflection and personal growth that she had.

Kiera describes how she has used her time to become more reflective and caring towards herself;

> 'Initially I thought I'd be lucky if I got six months and then I was lucky I got a year and then it kind of started stretching out. […] [I'm] trying to learn more about myself and understand more about myself as I go along, so that I can, I guess when the time comes as it does for all of us, to have some kind of peace of mind. Because I think if it had happened back then when I was diagnosed initially, I wouldn't have died with any peace of mind about myself or my life, whereas now I think I'm more reflective. I've learned to be a bit more caring towards myself and value myself a bit more. I mean, I'm not saying I have it all figured out, I certainly don't, and I'm as likely to have a meltdown and take to

> the bed on a bad day as the next person. Maybe I’ve learned how to say, ‘OK, right that’s done, now we have to get on with it again.’ My life has really changed now.’ (Kiera)

This additional time that Kiera has been living with terminal illness beyond her prognosis has prompted her to engage in self-reflection, self-compassion and learning. This additional period for reflection has provided her with an opportunity for personal growth and to gain peace of mind. While she’s conscious that she is still likely to have emotional despair and will likely continue to have bad days, she has learned how to remain positive during times of challenge and adversity and to value herself more. This additional time she has had, has been a period of introspection, where she has found a sense of peace, growth, self-compassion and meaning in life.

In summary, participants who have lived beyond their prognosis view each additional day that they live as a gift and a blessing, and use the additional and valued time as an opportunity for periods of reflection, learning and self-growth, as well as for finding new meaning and purpose in their lives.

5.3.4. Leaving a legacy: ‘I'd like to be remembered as somebody who died well, having lived well’

Participants have concerns about the type of person that they will be remembered as by others after they have died. Each participant speaks about their wish to leave a legacy and fervently hopes that their influence and spirit will live on into the future, beyond their death.

Participants describe how while they had been initially more concerned about surviving, they have over time, become increasingly aware about inspiring others beyond their death and enabling others to learn from their experience of living their lives. In this way, their legacy will outlive them and will continue to exist beyond their lives and their memory will live on through others in the future.

Layla speaks about wishing to be remembered as an inspiration to others;

> ‘I’d like to think that if they thought about me, they’d think about someone who says yes. […] I'd like to think that they can probably think of me and think, ‘oh well, she did that so I can do that. […] So yeah, to be somebody's inspiration in that way. I get told all the time, ‘you’re such an inspiration,’ but I don't really know what that means. But I'd like them to be inspired to think that they can do whatever they want to do.’ (Layla)

Being remembered as someone who had been open to living life is very important to Layla. She has far outlived the time that she had previously expected to live, and she has used this time to undertake new challenges and personal growth and has repeatedly said ‘yes’ to life. She wishes for others to follow her example and to live their lives with a positive attitude and to be inspired to accept any challenges that they may face without worry for the outcome.

Joanne talks about how she wishes to be remembered in her role as a family member and friend;

> ‘I suppose I've made a difference in the lives of people that I have known, and that I’ve been a good mother and a good friend. […] I suppose I want to be remembered for being kind. And you know, for being very open and very honest, and very approachable, and very hard working.’ (Joanne)

For Joanne, being remembered as a ‘good’ mother and friend is very important. She hopes that the roles that she plays within family and friendships during her lifetime, along with her values and virtues will live on in the memories of others. As she reflects on her life and legacy, the impact that she presently has on others and that she will leave behind after she dies, brings her a sense of peace and joy.

In a similar way to Joanne, Diana describes how she wishes to be remembered for her role within her family;

> ‘I'd love to know what my children think of me. That might be a start. I'd like to think that they thought I did a good job. And yet I know, they’ve told me over and over again. And funnily enough, my son […], he has given me so much praise of late about the life that he had, the life that we gave him, and it was such a joy to hear. So, I guess I've done something right.’ (Diana)

Diana demonstrates the importance she places on motherhood, and she wishes to be remembered for this important and significant role that she has played in the lives of her children, as she raised them from childhood to adulthood. As she reflects on her life and legacy of being a mother and having received positive communication from her son about the life that they shared, she feels content and at peace in the knowledge that she has been successful in this role and feels privileged to leave behind the legacy of providing her family with a very happy life together.

Similarly, Adele speaks about how her legacy will live on through her family members, her children and grandchildren;

> ‘My legacy to begin with would be my two beautiful children, which has led to two lovely grandchildren. So that's a legacy in itself. I’d like to think that I am fondly remembered by people.’ (Adele)

Adele is very proud of the legacy that she leaves behind, for being a mother and grandmother. She feels content and at peace in the knowledge that her legacy will live on through her family, both through her children and her grandchildren. It’s also important for her to be remembered by others whose lives she had touched during the course of her own life.

Kiera describes how her children are her legacy and how she wishes to be remembered as someone who was tried new things;

> ‘My children really have turned out to be good citizens, they're good people, they’re my legacy. As well, not being afraid to try new things, […] I did just keep going and I wasn't afraid to try new things. I was afraid but, I did it anyway. ‘Feel the fear and do it anyway,’ that’s kind of my mantra.’ (Kiera)

Kiera continues to live her life in ways to inspire her family and those around her about how they can live their lives and despite the suffering or fear that they may experience. She has been unafraid to take on new challenges, despite living with her terminal disease. The impact that she has on the lives of her loved ones enables her memory and inspiration to remain in the lives of others beyond the time of her death.

Other participants describe how they would like to leave a legacy by also looking beyond their immediate family and their wish to leave a positive impact on the world. They speak about feeling inspired to look beyond themselves and participate in research or advocacy to help others in their situation in the future.

Evelyn talks about leaving a legacy of research behind after she has died;

> ‘I joined the patient initiative programme, and I've never looked back. It’s given me a purpose and a focus basically for the last two years and I’m just loving it. Apart from my grandkids, it’s the love of my life you know. The area of research and anything I can do, even reading, following, whatever. It just gives me so much purpose and brightens up my day, just being involved. And the fact that patients have been made welcome is huge, you know. If I go tomorrow, I feel as if I’ve left a legacy that I've done something that might help my grandkids down the line, and I definitely see the future in research being brighter for that. Hopefully, my little input in amongst the thousands or millions will add to that light that I see for the future.’ (Evelyn)

For Evelyn, leaving a legacy of research that may potentially help her family and terminal cancer patients in the future is very important. She uses the metaphor of lighting the way for others who may find themselves in a similar dark situation. She believes that the ‘light’ of her participation and involvement in research may help other terminal cancer patients in the future, beyond her lifetime.

Ben also speaks about his wish to leave a legacy of helping other cancer patients;

> ‘I like the legacy that I help others with cancer now. Because I have such a positive outlook on it and attitude towards it, that my legacy is helping others with cancer. Definitely, 100%. I have people from all over the world and I’m not exaggerating, following my story and I get messages often looking for advice and support. And that fulfils me actually at the moment. That helps me with my own.’ (Ben)

Being remembered beyond death as someone who acts as a support and a guide for other newly diagnosed cancer patients is very important to Ben. He feels pride and finds purpose in the role that he has created for himself during his time while living with cancer. Through sharing his own experience and story on social media, he has become known as someone who can offer advice and comfort to others and who wishes to inspire them with his positivity as they begin their cancer journey.

Similarly, Adele talks about her wish to leave a legacy of inspiring others;

> ‘I’ve tried to get the word out there that you can be alive five years, ten years, fifteen years, twenty years after a diagnosis. So, I'd like that to be the legacy, you know, that you’re giving somebody strength somewhere.’ (Adele)

For Adele, through sharing her story of living life well beyond her prognosis, she wishes to leave a legacy of inspiration. She shares her experience of living beyond her life expectancy to inspire others who may share a similar experience to remain hopeful in surviving beyond their prognosis. By sharing her experience, she believes that other similarly diagnosed cancer patients can live with hope for their future and be inspired to find the strength to live through times of adversity, despite the many challenges they face.

Darragh differs slightly from other participants in his legacy wish, he describes;

> ‘I like the concept of ‘do no harm’ a lot. So, I’d like to think that when people remember me, they will say ‘no, he didn't hurt anyone.’ And then the other thing, obviously is that is whatever is left after both myself and my husband pass away we've made specific arrangements for charities we want money to go to. […] I'd like to be remembered as somebody who died well, having lived well.’ (Darragh)

For Darragh, being a respected and benevolent person, who inflicted no harm on anyone is the legacy he’d like to leave behind after he dies. His reference to the Hippocratic oath, which is based on beneficence, non-maleficence, respect for one’s autonomy and justice, suggests that he aligns his values with these principles. He is a kind person, who wishes for the remains of his and his husband's life savings to be donated to those less fortunate than themselves after their death. He wishes to be remembered fondly by loved ones and friends as someone who lived and died well.

In summary, all participants wish to leave their unique mark on the world after their death. While living with terminal cancer, participants have reflected at considerable length about how they wish to be remembered after they have gone. They have created their own legacy of what they leave behind, be it in terms of their family role, or in helping others. In essence, they wish to leave a positive impact on the world around them and this in turn, enables them to live out the time that they have left to live with peace in the knowledge of having had a life well lived.

In conclusion, following their terminal diagnosis, participants experience significant and intense periods of time which are filled with a hyper-awareness of time left to live, existential distress, concerns and worry about death and their future. For several participants, their most difficult and complex emotions are experienced when they are alone, during the darkest hours of night. During this time, they face their darkest fears about their time left and worries about dying and allow the suppressed emotions they keep from others in daylight hours to arise, be dealt with, and released. While participants live with periods of existential anxiety and significant emotional distress, periods of valuing time as currency co-exist, as participants experience each of these states continuously. Participants perceive time now as their most precious asset and choose to spend it wisely in engaging in meaningful activities and living purposefully. For those participants who have lived beyond their prognosis, they perceive that they are living on ‘borrowed time’ and have a deep appreciation of each additional day they are ‘blessed’ to live. Participants wish to inspire others through the life that they live and to be remembered fondly by those whose lives they’ve touched. In this way, they live in peace, knowing that they lived a life of value and meaning.

5.4. Negotiating a Changing Identity: *‘All of a sudden, I’m a patient with a chart’*

Participants describe their struggle with being identified as a terminal cancer patient and living with this new identity. They recall how they suddenly found themselves *Becoming the Terminal Cancer Patient* and were faced with the reality of living with this new aspect of their identity, which became a new and significant aspect of who they were in the world, and which dominated how they perceived themselves and how they were perceived by others. Although participants have at times found difficulty in *Shifting between Past and Present Identities,* and continue to experience periods of emotional distress, they also recognise that, while living with terminal cancer, they have changed as individuals in how they perceive themselves and in how they identify themselves in the world. Through *Re-defining Oneself* and finding new aspects of their identity, participants have been able to adapt to their new lives as they live with their illness, which has had a positive impact on their wellbeing. Several participants have experienced personal growth while living with terminal cancer and have become stronger emotionally, which has helped them to embrace their new sense of self.

5.4.1. Becoming the terminal cancer patient: ‘It’s very hard to adjust to seeing yourself as a cancer patient’

Participants speak about experiencing significant distress as they found themselves being identified as a terminal cancer patient. They talk about how this new identity became suddenly and overwhelmingly dominant in their lives. They describe how they found it immensely difficult to come to terms with the fact that they were being identified as a terminal cancer patient and they recall how they felt unable to make sense of their situation. Several participants highlight how they struggled with the tension between this overwhelming and dominant new identity and with their other identities in terms of their social roles at home and at work. The loss of their previous identity caused a sense of grief, anger, and emotional distress as they attempted to adjust to their new identity of living as a terminal cancer patient.

Kiera, having recovered from a primary cancer ten years previously, describes how she experienced difficulty in adjusting to identifying herself as a terminal cancer patient and becoming a cancer patient again;

> ‘It was one of those cancers that doesn't respond to chemotherapy and so, if you had a re-occurrence, if it didn't get cured from the initial surgery, that was pretty much it. I knew that and I had been living with that for, like, 10 years, that worry about it coming back or not being any treatments. […] It's very hard to adjust to seeing yourself as a cancer patient. Although the second time I went into hospital and I was now a cancer patient again, it wasn't as shocking as the first time I walked into the hospital and looked up and

> saw an oncology sign over my head and thinking like, ‘what the f*** am I doing here?’ I never saw myself in this department in the hospital, it wasn't part of my plan.’ (Kiera)

For Kiera, being diagnosed as a terminal patient was not an experience that she had foreseen as having in her life. Hence, she has struggled immensely to come to terms with the fact that she has found herself in a clinical setting again and has had to confront her reality of living now as a terminal cancer patient. She experienced significant shock and distress in the move from her identifying herself as a cancer survivor to becoming a terminal cancer patient.

In a similar way, Evelyn recalls how she found it difficult to cope with the idea of being identified by others as a terminal cancer patient;

> ‘I didn't want to be branded with, you know, that I'm dying from cancer. I wanted to just live as best as I could with cancer and with my own kids and the family and grandkids, everything.’ (Evelyn)

Evelyn does not wish to live with the label of being a terminal cancer patient, but instead continues to see herself as someone who is living as best a life as she can while living with her terminal condition. She wishes to identify herself in line with the important roles that she has in her life such as a mother or grandmother, which focus upon living well rather than dying from cancer.

Several participants talk about their struggle to change how they identified themselves in terms of their former social roles and to identify themselves as terminal cancer patients. Adele speaks about her struggle with her changing identity;

> ‘When I got diagnosed with stage four [cancer] at the very beginning, it was really shocking to even think the word cancer. […] In my mindset, that’s what I am, I am a person who goes to work every day. And I didn’t want that to change. […] So, like, all of a sudden, I’m a patient with a chart. And a medical record number […] it’s so traumatic in many, many ways. And then, because it was stage four, I wasn't going through the chemotherapy, the radiotherapy, where you get to meet lots of cancer patients going through similar things as you.’ (Adele)

The change in Adele's identity from being an employee who worked every day to being a terminal cancer patient was a cause of intense emotional turmoil for her and this significantly impacted her sense of self. She depicts her experience of significant distress when she was forced to take a step back from her employment role, as she suddenly found herself being identified as a terminal cancer patient. She highlights that the shift in her identity and sense of self was one of the most traumatic elements of the terminal cancer experience, which resulted in significant emotional distress due to the loss of this significant aspect of her identity. Also, the specific terminal nature of her disease meant for Adele that she could not undergo curative treatments which other cancer patients received and thereby had fewer opportunities to meet others who might have had a similar diagnosis to her.

Similarly, Ben describes how he has felt about his changed identity;

> ‘But then my life changed because I was told I wasn’t allowed to work in construction anymore. […] So, I was put straight onto an invalidity pension. I was scared sick of it. […] It kills me not to work. It absolutely kills me not to work. I worked from a very young age in life. I was ten or eleven. Delivering leaflets, selling newspapers, working on the farm in the summer picking fruit, I was always doing something. Now, I'm not doing anything, and it does play on me.’ (Ben).

Ben's change in identity from being a worker to being someone who was suddenly no longer allowed to work in construction anymore caused him significant emotional distress and negatively impacted upon his wellbeing. As he has been involuntarily put on an invalidity pension, he has found the lack of activity in his life difficult to deal with. This has resulted in him losing his sense of identity of being an independent person earning his own income to becoming a terminal patient who was dependent on income support. Further, he describes feeling ‘scared sick’ of the invalidity pension, and this has negatively impacted his mental and emotional wellbeing.

In contrast, some participants remained in employment following their terminal diagnosis and during their associated cancer treatment. However, participants who remained in employment during this time describe the negative effect that their cancer diagnosis had on their employment and career outcomes. This also negatively impacted upon their sense of identity.

Layla describes how she felt about changes in her career and sense of identity;

> ‘You know, I loved my job, I loved where I was going in my career, but I wasn't able for the hours. I was having a lot of treatments at the time. I was having various surgeries and having a lot of time out and then the company was taking me away from being operational and putting me into office-based duties. That didn't suit me, so I had to give that up. So that was probably one of the harder things I had to give up, [I was] angry, very angry at the time.’ (Layla)

For Layla, having to cease working in a role that she had been very happy in and where she had enjoyed career success had a negative impact on her, as she felt ‘angry, very angry at that time.’ This was a significant and life changing loss of a central aspect of her life, as she tried to adjust her life to adapt to her changing health needs resulting from her terminal diagnosis. She subsequently ended up leaving her employment reluctantly, which caused significant anger and frustration for her as it was not an aspect of her identity and life that she willingly wanted to part from.

In summary, participants experienced a loss of their sense of self and identity following their diagnosis with terminal cancer. They struggled with being a terminal cancer patient and found it difficult to discuss the reality of this situation - that their disease was incurable and that their identity would never be the same again. Additionally, with changes in their social roles at home and at work, their sense of self and identity was negatively impacted, resulting in significant emotional distress.

5.4.2. Shifting between past and present identities: ‘You have this weird dichotomy, […] there’s no handbook that tells me how to manage that disjoint’

Participants highlight how they struggle to part ways with the life that they once lived and the person they once were following their terminal cancer diagnosis. As they adjust to living with terminal illness, participants experience a change in their social identity and speak about a disconnect that exists between how others perceive them and how they perceive themselves. Participants describe their struggle to make sense of their new sense of self and their changed identity.

Darragh describes his struggle to make sense of his identity;

> ‘I can no longer be normal. But part of my brain is trying to make me act normal and society and this is me impressing societal requirements on myself if you will. Society expects me to behave normal because I look well. I went and spoke to my counsellor the other day and she said, ‘you look fantastic.’ I went to see the oncologist last week and he was there and his physician and his sidekick, and the two of them going ‘my God you look amazing. I've never seen anybody's hair grow back as quickly.’ They were going ‘you’ve got your hair and your beard, the whole thing.’ […] There is ongoing pain and discomfort, and I can take staggering amounts of medication every day, just because half my organs and my insides are gone. And that's fine. You can live with that. But you have this weird dichotomy, […] there’s no handbook that tells me how to manage that disjoint

> in terms of how I think how normal people should define a normal purpose, a person, of course, how you're supposed to fit into society, but still, at the same time how you are supposed to be a part of society that is supposed to be wrapped up in cotton wool and not do or go anywhere. And it's a really interesting place to be because you have to really have to figure it out yourself. I'm not sure how to do that.' (Darragh)

Darragh struggles to live with his illness as he cannot conform with society's view that both 'looking well' and 'feeling well' are correlated with each other. While he continues looking well externally, he feels physically unwell within himself but feels that he has to manage this to fit in with societal expectations and be 'normal.' Due to his illness, he no longer feels like a normal member of society and is unsure about how he fits in with others as they do not perceive him to be included within society due to his terminal cancer and perceive him as having to be 'wrapped up in cotton wool.'

In a similar way, Kiera recalls how she has struggled while adjusting to the reality of being a terminal patient;

> 'I was angry as well, I was angry at this stage. I was angry with the system, angry with the cancer […].' My kids were moving on with their lives, I didn't know what my purpose was anymore […] I'm always going to be this stage four patient, what's my purpose in life? You can go to some very low, dark places.' (Kiera)

Kiera has felt a lack of a life purpose within her life, as she has given up former social roles and saw that other peoples' lives were moving on, but she perceived hers was stagnant. This has caused her significant emotional distress. She highlights that she feels that she no longer has a purpose in life and that this lack of purpose causes her to experience negative emotions and question her own future potential as a terminal cancer patient. She describes how the loss of being in employment results in her feeling that she lacks purpose in life, and this has a negative effect on her emotional wellbeing.

In a corresponding way to Darragh, Kiera also describes how, although her outward appearance is not one of how others might typically perceive a terminal cancer patient to look like, she repeatedly needs to explain to friends and family members that she nonetheless is living with terminal cancer;

> 'Nobody would pick me out as the stage four cancer patient. Even some people say to me, 'sure you're not a stage four cancer patient now.' I'm like, 'how exactly do you think that is?' I'm always going to be an oncology patient, I'm always going to be a stage four patient, I'm always going to have to have scans, bloods, pointless conversation about cancer and it could kick off again at any time, so I'm still very much living with cancer.' (Kiera)

Kiera experiences a sense of divide between her physical appearance and her own feelings as she still lives with her terminal illness. While others perceive her as being well again as she is not experiencing visible physical symptoms of her disease, she will always live with her terminal diagnosis and be subject to appointments and associated treatments for the rest of her life. The lack of understanding from others and the consistent need to remind them of her condition frustrates her as this is not something that she will ever live without in the future.

Linda also reflects upon how she feels conflicted by physically looking well while feeling physically unwell and psychologically distressed;

> ‘Like physically at the present time, you wouldn't know there was anything necessarily the matter with me. You know, if somebody saw me, they would be quite surprised to be told, ‘oh, you know, this woman's going to die.’ But psychologically, I've taken a bit of a hammering.’ (Linda)

This conflict between Linda’s internal and external states have led her to feel misunderstood and alienated in living with her illness. This impacts upon her sense of identity as she is not visibly a terminally ill cancer patient but at the same time, she cannot maintain the other roles that she once played in her life. This sense of liminal space between different identities has caused her significant psychological distress.

In a similar way, Joanne speaks about experiencing conflict between her outward identity and her own sense of self as a cancer patient;

> ‘I come across as being very strong and very independent. And I suppose I've always been the one that holds so many things together. And that's what I do. So, I suppose what

> I did realise in the middle of it all was that I'm there and I'm supporting a whole lot of people. And I actually felt that there was nobody really there supporting me.’ (Joanne)

Joanne experiences conflict between how she is identified by others and how she has learned to view herself as she lives with terminal cancer. This has caused her feelings of isolation while living with her illness. As others perceive her role in life as being the supportive one who ‘holds so many things together,’ she does not receive the support she needs from others and experiences a conflict between her social roles and her identity as a cancer patient.

In summary, participants in this study highlight that they have experienced a shift in their social identity and have struggled with a disconnect between how they identify themselves and how others identify them as they adjust to living with their diagnosis. This has contributed to participants struggling to make sense of their changed identity as they live with terminal cancer.

5.4.3. Re-defining oneself: ‘I’ve become stronger and more confident in who I am’

Although participants still continue to struggle with a shifting identity, they also recognise that while living with terminal cancer, they have changed as individuals in how they perceive themselves and in how they identify themselves in the world. Several participants acknowledge that they have become stronger and have experienced personal growth through the diagnosis and experience of treatment. Through this, they have become more able to re-define their sense of self.

Ben talks about his experience of personal growth while living with terminal cancer;

> ‘I have changed as a person. I’ve become stronger and more confident in who I am. Definitely taking nothing for granted. [Cancer has] made me a stronger person. Going from one battle to the other, getting through the first battle, the second battle, third battle and getting through it, it just gave me more confidence and made me a stronger person. […] I've never been happier in my life than I am now. Never, ever, ever. No, it’s just strange, I think. I love my life the way it is at the moment, I love what I do, I love how I am. I was involved with drink and drugs for a long time when I was younger. And I absolutely hated myself for it. But I actually love the person I am now.’ (Ben)

For Ben, each cancer diagnosis is seen as a ‘battle,’ a fight to be fought. He views himself as the warrior who has grown in confidence and strength through the course of each battle, which he has overcome on each occasion. This personal growth and development through his ‘battles’ have helped him to develop and embrace a new sense of self, as someone strong enough to grow through and live with his biggest ‘battle,’ his terminal cancer diagnosis. He lives with a re-defined and renewed sense of self which has allowed him to eliminate any elements that he deemed unhealthy or not positive to his wellbeing from his life. This allows him to live well and love his life which has increased his level of wellbeing, despite his terminal diagnosis.

Similarly, Layla describes her personal growth and changing sense of self during her experience of living with terminal cancer;

> ‘Like I'm not going to get better, and I haven't died and I'm actually, like, well enough to do things, so now I do try and like I've gone to university, and you know there's things that I am doing that a few years ago I wouldn't have considered. Things like even throughout this part of my life, things are still changing in the way that I accept it or the way that I kind of live with it.’ (Layla)

Here, Layla highlights that the pursuit of new goals and opportunities has helped her to discover and embrace a new sense of self and to feel a part of the world around her as she continues to live with purpose, despite her terminal cancer diagnosis. The experience of terminal cancer has acted as a catalyst for her to pursue new opportunities and attain previously unfulfilled goals, such as returning to education. These experiences enable her to live well with her disease.

Layla speaks further about feeling gratitude for this growth and changes in self-identity during her terminal cancer experience:

> ‘Looking back, I'm actually kind of grateful for it because I like the direction my life has gone in since.’ […] ‘I’m happier, it sounds crazy but, actually, my life is better now than it ever has been, other than that one and I'm gonna say that one small thing [cancer], it’s not a small thing, but it's the only real negative thing in my life. Everything else kind of worked out really well, and that's because I've given myself space to put time and effort into that like.’ (Layla)

For Layla, cancer has become a smaller part of her life and no longer defines her sense of self. She feels gratitude for the experience in hindsight, as she has had the space and time necessary to create the life that she wants to live. While she originally perceived that having terminal cancer had a significantly negative effect on her life, she has recognised that this experience has enabled her to open doors that she didn't think were possible and has allowed her to discover new aspects of herself. Hence, she became grateful for this experience, despite its negative aspects, as it has had a positive effect on other parts of her life.

In summary, participants have become stronger emotionally and have experienced growth while living through the experience of terminal cancer. As participants have re-defined and embraced their new sense of self and purpose, they have begun to live their lives in more positive and meaningful ways. The growth that several participants have experienced through the challenge of living with terminal cancer has enabled them to connect with their authentic and true selves and to find happiness, increased wellbeing and gratitude for positive new experiences. Participants have been able to live with less worry and feel more at ease about their prognosis and realise that they can have a good quality of life despite their disease.

In conclusion, participants have struggled with being identified by themselves and others as a terminal cancer patient and with their adjustment to living with this new identity. They have struggled with coming to terms with this sudden and overwhelming change in identity and leaving behind their former social roles. As participants adjusted to their new identity, they experienced a disconnect between this and their social identity, which resulted in extended periods of feeling emotional distress and frustration. While they continue to experience these emotions, participants also recognise that, while living with terminal cancer, they have changed as individuals. Through discovering new aspects of their identity, participants have been able to adapt to their new identity, which has had a positive impact on their wellbeing. Participants have experienced personal growth while living with terminal cancer and have become stronger emotionally, which has helped them to embrace their new sense of self.

5.5. Finding Comfort through Connection: *'I don't have to worry about it […], I'll go through the pearly gate'*

Participants speak about how they find comfort in connection while living with terminal cancer. This includes *Connecting with Self*, with God or a higher power, and with the world around them. By connecting mind and body, participants find a greater sense of balanced emotions, and find new ways of living with self-compassion and wellbeing. *Forging a Connection with God or a Higher Power* helps participants to find comfort and support. *Feeling Connected to Nature* and the world around them helps participants to find peace and a greater sense of wellbeing.

5.5.1. Connecting with self: 'I just go with the flow. I listen to my body and my body tells me what to do'

Several participants speak about how they find that connecting more deeply with self provides them with a sense of emotional balance, self-acceptance, and self-compassion.

Joanne describes how her experiences of alternative therapy have helped her to connect more deeply with herself;

> ‘I’ve done a lot of work on myself. […] I’ve done an awful lot of Reiki, I’ve done acupuncture. […] And, I suppose, you know, you don't have to be that strong person. And you don't have to be out there. You know, being strong and independent for everyone, it is okay to show your weaknesses. And it's okay to cry in front of people. And it's okay to feel vulnerable. And that's all very human. And, you know, I suppose I had lived this very strong, independent life for so long. And like that, I worked in management and different things, and had people looking up to me all the time. And I felt as if I had to hold all of that together. And I don't. But you have to learn these things the hard way.’ (Joanne)

For Joanne, spending time on a regular basis to engage in alternative therapies has helped her to balance her emotions while living with the challenges of terminal illness. This engagement with alternative therapies helps her to connect her body and mind. Through spending time in self-reflection, she has found a deeper self-awareness and acceptance of her own vulnerability while living with her terminal condition, which has helped her to increase her self-compassion and emotional wellbeing.

In a similar way, Diana speaks about how connecting her mind and body helps her to find balance;

> ‘I found reflexology fantastic. But I think what has helped me more than anything else is that I just go with the flow. I listen to my body and my body tells me what to do. And that may seem strange, but it's my way of coping.’ (Diana)

By regularly cultivating a connection between her mind and body, Diana experiences a sense of balance. As her mind and body align, she believes she can trust the ‘flow’ of life, and this informs how she lives her life.

Darragh describes how he connects with himself through attending regular counselling sessions;

> ‘Going through therapy definitely settles you as well. So, you still have your ups and downs and your highs and lows and stuff. But, certainly for me, being able to reach out to a counsellor is hugely important. Just trying to keep on an even keel. […] It's really just about helping you pick yourself back up. I think it helps you centre yourself and kind of realign yourself.’ (Darragh)

Darragh’s regular attendance at counselling sessions helps him to connect with himself on a deeper level to learn to balance his emotions. Counselling helps him to engage in deep reflection and introspection, to find ways to manage his emotions and to find balance between the constant fluctuations between positive and negative states in order to bring himself back to a sense of equilibrium and balance.

In summary, connecting body and mind facilitates participants in finding a deeper sense of self-awareness, acceptance of their own vulnerability and overcoming emotional distress, and is instrumental in how they live with their cancer diagnosis.

5.5.2. Forging a connection with God or a higher power: ‘I consider God a friend in my life, […] he has helped me and supported me’

Participants speak about how forging a connection to their concept of God, or a higher power has been a source of comfort and support, which has helped them to live with greater sense of peace and meaning while living with a terminal cancer diagnosis.

Diana describes how she connects with God and her deceased family members and friends;

> ‘I do talk to people who have died, my family in particular, and those closest to me. I just say, you know ‘God knows my history’ and I'm happy. I don't have to worry about it. I hope I’ll go through the pearly gate. I wouldn’t like to think otherwise but that’s not my decision, I suppose, so I don't worry about it.’ (Diana)

Diana’s conversations with her loved ones who have died enable her to confide her innermost thoughts and fears in those whom she trusts and has complete faith in, in the knowledge that she will not be let down. Her belief in God as a parental figure who she can speak to and who will not forsake her, and her continued relationship with her beloved deceased family members provide her with a great sense of comfort and protection as she has nothing to fear about death and the afterlife beyond.

Joanne speaks about her connection with God who she considers to be her friend in life;

> ‘I consider God a friend in my life, and, like that, he has helped me and supported me, all through my life in various different ways. And I would sit down, and I would say my prayers every night before I go to sleep, and I will include in my prayers when I’m praying to God, I'm also praying to mammy and to daddy and to my brother, and to my few friends that are in heaven. […] So, when I'm doing all of those prayers to God, and then God is good enough then to help me and support me and get me through whatever shit that’s going on in my life, and then I feel that if God is my friend, and if any friend that I have, does something like that for me in this world, and I say thanks to them, so my way of saying thanks to God is to go to [religious site for reflection] and to give God two or three days of my time fasting in peace, in prayer. And that's my way of saying thanks to God.’ (Joanne)

Joanne perceives God as a friend in her life, who has supported her throughout her life and who she can turn to in times of challenge. She finds comfort and support in her strong connection with God, who she connects with on a continual basis. She engages in regular religious practice, such as daily prayer, and intermittent attendance at religious sites for meditation and prayer as a means of showing gratitude to God for his help as a faithful and lifelong friend to her. Her staunch belief in the afterlife and daily connection with deceased family members and friends are sources of comfort and support, as is her deep reciprocal connection with God, her loyal and trusted friend who supports and guides her in her most challenging times and in return, she shows deep appreciation and gratitude.

Other participants who do not consider themselves to be religious, but would rather see themselves as spiritual, also speak about their connection with a higher power as a source of comfort and support, which helps them to find meaning in life while living with their terminal disease.

Evelyn describes her belief in a higher power and how her connection with this higher power helps her;

> ‘Even though I’d call myself a non-believer, I still have something there that I’ve held onto all my life, and I still feel something spiritual with it. And I do feel something. I'm never sure is it someone from beyond the grave spiritually helping or if there is a divine, I’m never sure. […] ‘Cause I often found myself like actually talking to my mother who has passed on you know, or one or two other people, even saying, ‘if you can do anything from there, help at this stage.’ A few times, I actually felt I might have got a bit of help there. I suppose we like to believe, don’t we?’ (Evelyn)

Although Evelyn considers herself to be a ‘non-believer,’ she does believe in spirituality and the existence of a higher power which guides her in life. She has felt guided throughout her life by a spiritual presence and believes that this benevolent presence has supported her in the past when she asked for help. She’s unsure whether this presence was her deceased mother or other deceased loved ones, who she spoke to. She finds comfort in her belief that there’s some divine help available to her, which she has previously received in times of need. This belief in a spiritual and benevolent presence is a source of comfort and support as she lives in the knowledge that this will be available for her once again to draw upon, should she need it. In this way, she believes and trusts that she is not alone while living with her terminal disease.

Diana also speaks about how she finds comfort in her connection with a higher power;

> ‘It’s a nice comfort to know that there is something beyond this life which I believe, whatever it is, I don't know. It would be nice to think you would meet the people you've lost. I don't know, I don't think it would be a worry. I don't think I'll have a worry in the world on the other side.’ (Diana)

Although Diana perceives herself as non-religious, she believes that there is life beyond this world. She finds it comforting to believe in the existence of an afterlife, where she will meet deceased loved ones once again and where she will no longer have any of the worries that she felt while living in this world.

Similarly, Darragh talks about being spiritual and having faith in a higher power;

> ‘I like that concept that we are part of a greater something and we all interact and there is a cause and effect. […] that's my spirituality. […] Faith is very different from religion.

> So, I suppose I have a certain amount of faith. But it’s not religious based. And it's not God based. It's just based on my reality.’ (Darragh)

Darragh considers himself as not being religious, but rather to be a more spiritual person, who is connected to others and ‘something greater’ within the world around him. His spiritual beliefs provide him a greater sense of meaning and purpose in his life that is not associated with any formal religion. By maintaining his own spiritual beliefs, he lives with a greater sense of connection and meaning.

In summary, forging a connection with God or a higher power enables participants to find a sense of comfort and support. Trusting in God or a higher power helps participants to feel peace while living with the knowledge of their finitude.

5.5.3. Feeling connected to nature: ‘It’s almost a bit of a meditation for me’

Several participants describe how spending regular periods of time connecting with nature helps them to find peace and a greater sense of wellbeing while living with terminal illness.

Layla describes how spending time connecting with nature helps her to find peace;

> ‘The beach [gives me peace], walking, I love to walk. I just chuck my tent on my back and walk. Last year I walked across Ireland, this year I walked [county]. It’s almost a bit

> of a meditation for me, on my own or with my dog, walk for as many miles as I can in a day, pitch a tent, do it again the next day, repeat. Yeah, that's my thing.' (Layla)

Layla finds peace through her connection with the world around her and being active within it. Walking for extended periods alone or in the company of her dog and spending nights in the seclusion of nature serve to be a meditative experience for her, which provides her with a sense of peace and contentment. As she finds peace, she feels a sense of increased wellbeing.

Adele also talks about feeling connected with nature;

> 'I'm just a person who thinks the world is a Church in a way. So, if you get out into nature and get out for that walk every day, and you just listen to the bird songs, breathe in the air, look at the sky, look at the things around you, that's what gives me my energy to go about every day. I think just being out in nature and out in the fresh air and making the most of out of every day is what's important to me at the moment.' (Adele)

Adele connects with nature in a spiritual way. Spending time walking outside each day, while using her senses to engage in mindful connection with nature such as listening to birds, breathing in fresh air, and seeing the beauty of the world around her, help her to find peace and to feel a greater sense of wellbeing and positivity and to find meaning in her life.

Joanne describes how spending time alone connecting with nature helps her to release negative emotion;

> ‘So, what I used to do was, I used to go down to [rural place alone in a forest area] and I’d go down there for two or three days. And that would allow me the space to sit and even cry, when I couldn't cry in front of people. And I could do it there. […] I could sit on a mountain, I could do whatever I want. And I could cry, and it doesn't make a difference to the world. Because if you don't let it out, you're holding it in. And you need to have that space as well to do that. And you can't do it in front of your family, because you're upsetting them. (Joanne)

For Joanne, spending time alone connecting with nature provides a space for deep reflection about her terminal cancer experience and for the release of her suppressed emotions around the reality of living with her situation. Through taking time away from others to connect with nature, she can freely and easily release her negative emotions without upsetting others around her. While being alone and connecting to the expansive space and silence of nature, she can release her challenging emotions without fear or worry of interrupting anyone.

In summary, for these participants, spending time connecting with nature and appreciating the beauty in the world around them helps them to release suppressed emotions and to find peace within. As they become more in touch with the world around them, they gain a greater sense of wellbeing while living with their terminal illness.

In conclusion, connecting with self, God or a higher power and nature can have a significantly positive influence on how one lives with terminal illness. These connections are a source of support, peace and increased wellbeing for participants during their most challenging of times. Participants trust that these connections will continue to provide them with a sense of comfort, so that they may live with less worry about the future.

5.6. Navigating the Social World: *'The support that I have is incredible, and is critically important to my well-being emotionally'*

All participants speak about their experience of navigating the relationships that they have in their lives, as they live with terminal illness. Several participants speak about *Feeling Detached from Others*, both family members and friends, who they had previously had close relationships with. This detachment has been experienced as both physical and emotional distancing from others. These participants describe how this detachment from others has caused significant emotional distress to them, as well as alienation and feelings of isolation. However, while some relationships have been lost or been distanced, other relationships have deepened. *Relating to Other Terminal Cancer Patients* helps them to feel supported, comforted and understood. Several participants speak about the importance of *Cultivating Meaningful Relationships* with family members and close friends. They describe how they find meaning and purpose in these close relationships as well as having deep appreciation and gratitude for them. Each of these relationships are a source of comfort to participants to help them to live with increased wellbeing and to feel more positive towards the future, while being acutely aware of their own finitude.

5.6.1. Feeling detached from others: ‘You learn not to open up and talk to people about this stuff’

Each of the participants speak about experiencing difficulties in their relationships with others while living with terminal disease. Some participants feel detached from family members, while others speak about feeling emotionally and physically detached from previously close friends. These participants posit that this is due to the inability of others to speak about the realities of living with terminal disease and having conversations about dying. Most of the participants describe how they experience emotional distress due to being unable to talk about their situation with those close to them. In some cases, participants have come to avoid having conversations with others about their illness to protect themselves from feeling emotional rejection, while in other cases, they avoid disclosing information to others in an effort to protect them from upset or emotional burden. By not feeling able to talk to close family members and friends about their illness, they feel disconnected and alienated from others.

Layla speaks about feeling emotionally detached from family members and feels unable to speak to those close to her about living with terminal cancer and her poor prognosis;

> ‘Knowing that you have a life limiting illness, it's something I've never really got my head around. I find it difficult to bring that to other people. […] My mum is difficult when it comes to things like medical things. So, she wouldn't be overly supportive as in, she kind of shuts down. She doesn't take the interest that you might imagine. So, I don’t really talk to her about it. She’s just a bit quirky that way, I think she has her own phobias around anything medical. [She’s] not the person if I had worries you know, if I needed

> support […]. She's just not involved in that side of things and that was hard to start with, but now I very deliberately keep her separate. Because that way, I can't be affected by it. She can't let me down if I don't allow her to be a part of it. So, that’s how I deal with it now and that works well for both of us, I think. So, I have a brother, he lives in [country]. We’re fine, we get on, but we don't really see each other very much and then I have a sister. Well, […] she's great but she’s a teenager, and she lost her dad when she was nine so I kind of feel like I need to protect her a little bit from the realities. She knows that I'm sick and she knows what might happen and she sees me going through chemo and all that sort of thing, but she wouldn’t be the person that I’d go and talk to about it. I kind of rely on friends really for [emotional support.]’ (Layla)

Layla believes that her family members are unable to provide her with the support she needs. She avoids even attempting to ask for emotional support as she believes that it would not be available from her family. This particularly relates to her perceived relationship with her mother. She has made the decision not to share her thoughts and feelings about her terminal cancer experience. By actively choosing to separate her mother from her experience of terminal illness, she protects herself against the risk of being disappointed and emotionally rejected by her mother. For this participant, it seems preferable for her to protect herself from the emotional pain of not being able to share her experience of living with such a significant disruption to her life than to leave herself open to being vulnerable and to try and discuss this with her mother. She also does not have a close relationship with her brother who lives abroad. Additionally, her wish to protect her teenage sister from the reality of her illness means that not sharing her experience with family members seems preferable to seeking emotional support from them.

Evelyn also describes how she does not seek emotional support from some of her family members as she attempts to protect them from the reality of her finitude;

> ‘Sometimes you’re even trying to protect people. I even find after even 5 or so years, there's still people in my family that I don't talk about how I feel today. They can't handle it, even the word cancer is difficult for them. So, I don't get to share how I am or how I’m dealing with cancer with certain members of the family. It’s just left out, totally blanked as if it doesn't exist.’ (Evelyn)

Evelyn does not want to burden others with her worries and would rather struggle alone with the reality of her disease herself than see family members having to deal with it emotionally. Hence, she chose to ignore her own feelings in the presence of some family members. Instead of gaining emotional support from those around her, this participant suppresses her own thoughts and emotions regarding her terminal illness and shields others from this part of her reality, in an effort to protect them from the burden of having to discuss her diagnosis and face their fears about the experience of terminal cancer and their own mortality.

Similarly, Kiera speaks about feeling emotionally detached from family and friends during her terminal cancer experience;

> ‘People were very good, but I did feel that people didn't know what to say to me either. I did feel like a lot of people backed off, backed away from me. I have some good friends

> who have stuck by me, but it's a lonesome kind of place and you're keeping your feelings in as well because you're protecting everybody around you as well. I mean I couldn't sit at the table and cry every day because I mean, what was that going to do to my family as well? […] Nobody wants to f**king listen to me. I can’t talk to family, I can’t talk to friends because people who are too close, you don't want to be upsetting them. And then, I've had the experience before where you open up to people and then they back off, because this is too much, it's too heavy, they don't know what to say to you. They end up distancing themselves, so you learn not to open up and talk to people about this stuff.’ (Kiera)

Kiera struggles with the physical and emotional distancing of friends and family members since the time of receiving her terminal diagnosis. Friends distanced themselves from her after she had asked for support as they felt unable to help her. This has caused her to not seek emotional support from those around her, but instead she has attempted to protect them from knowing the reality of her condition. For this participant, the wish not to burden family members and close friends with her concerns and protect them from her worries means that she feels a sense of loneliness and isolation. The past negative reactions of others towards her sharing her emotional distress means that she has learned to suppress her thoughts and emotions, as she struggles emotionally alone in silence.

Adele talks about how she doesn’t want to share information with her family and friends;

> ‘I think there’s an awful lot of covering up that goes on with friends and family. You cover up an awful lot. […] Things that go on, I deal with kind of privately and I don't want to share them. I think that's really more than anything, because I know I can deal with it. And if I were to constantly tell [family] all the things that I know, they'd be petrified. So, yeah, I know, I can deal with it. And just drip feed small amounts of it but I don't want to change their lives. I’ve two young adults and two grandkids, and I want my daughter to enjoy motherhood as much as she can and not be worried about her mother. And, at the moment, we're very lucky that my health is as good as it is. And she hasn't had to worry about me too much. Like, in my head, I don't know how much they all worry because I don't ask them. I feel that maybe their friends would support them.’ (Adele)

Adele has chosen to address her health issues alone and has decided not to share all of the information that she had actively sought out for herself with family members and friends regarding her terminal condition, in an attempt to protect them from further worry and concern for her health. Her motivation for doing this is her concern about not allowing the lives of others, such as her daughter’s experience of motherhood to be put on hold, while she is living through this challenging experience. However, by withholding information and protecting others from her reality, she does not allow them the opportunity to support her emotionally and this can alienate her further, as she has nobody to speak to about her experience of living with terminal cancer.

In a similar way to Adele, Joanne describes her wish not to share how she’s feeling with others;

> ‘Since my parents were dead, and I was the next oldest, my sisters are younger than me, so I was already after slotting into the role where it was now as if I was the parent of them as well. And I too had to be very much aware of how they were feeling because, like that, they come to me all the time for support and different things. So, I suppose what I did realise in the middle of it all was that I'm there and I'm supporting a whole lot of people. And I actually felt that there was nobody really there supporting me. And that's a big thing. […] All of a sudden, I felt very vulnerable. And I just wanted somebody to put their arms around me and hold me. And it was actually, probably, I was going around, and I could feel in a way that my heart was broken. And I would put my arms around so many people, but I had nobody to put their arms around me. And that actually really, really hurt. […] And I suppose I felt if I let my guard down and show them how fearful I was and how vulnerable I was, if I started crying, I mightn’t stop.’ (Joanne)

Joanne has adopted the role of being a parental figure in the lives of her younger sisters following the death of their parents. In this role, she has acted as a support to her sisters and other family members and has been reluctant to disclose her own worry and vulnerability to them. She has chosen to suppress her own painful emotions and hide them from her family members. She does not feel she has support available to her and believes herself to be in a vulnerable position of feeling alienated and alone in her emotional struggle.

Other participants have experienced physical and emotional detachment from friends, due to the inability of others to speak about dying.

Ben talks about how he has lost contact with some friends and has been avoided by others since receiving his terminal cancer diagnosis;

> ‘I’ve no idea why I’ve had friends that avoid me because I have [terminal] cancer. And that is actually hard. I remember walking down the street one day and a fella seen me coming and he crossed the road because he didn’t want to talk to me because I have cancer. Some people feel awkward talking to people with cancer. I’ve lost friends over it. Friends have stopped contacting me. I used to make the effort all the time. I just couldn’t be bothered now, which is hard like, because a lot of my friends, they find it hard to talk to someone with cancer. They find it hard to deal with it in themselves. But me, I’ve no problem with it. In that way, I suppose friendships have collapsed. And I think it’s down to the fact that people don’t know what to say to people with [terminal] cancer.’ (Ben)

Ben found initial difficulty in understanding why he began to lose previous friendships following his terminal cancer diagnosis. He posits that this is due to the inability of others to cope with speaking about living with terminal cancer and thereby face the possibility of having to deal with their own finitude and mortality. He recognises this avoidance by others is not personal, but rather a shortcoming of their ability to face the reality of living with terminal cancer and living with dying. Nonetheless, this is an isolating and alienating experience for him, where he feels disconnected from others, and which prevents him from being able to rely on and depend upon the support of friends to talk about his fears, worries and concerns for the future.

In a similar way, Linda describes how she struggles to speak with friends about her terminal cancer experience;

> ‘People always say, ‘well, how are you?’ But the reality is, nobody really ever wants you to say, ‘actually, I feel like shit.’ People, what they're hoping you’ll say, is ‘I’m grand, I’m fine, I’ve never been better.’ And then you'll say to them, and ‘how are you?’ And they'll say, ‘oh, I'm grand.’ Because really, nobody wants to have to engage with dealing with people's life shit. But it's even more so when you've got [terminal] cancer, because let's face it, you say to someone with cancer, ‘how are you?’ Nobody wants you to sort of say, ‘oh, this bit of me dropped off yesterday, and psychologically, I'm a basket case, and I cry a lot.’ Nobody wants to know, and neither would I expect them to want to. Yes, people feel obliged to go through the motions of asking you. But I doubt very much that people really want an honest answer, because then they have to deal with that answer or respond to it in some way. Which can be very difficult for people, not everybody's equipped to do that. […] But I think everyone would be happier if you used pleasant euphemisms for things that made things sound less grey and black and white and more sort of rosy coloured. Let’s get real, that's the reason why the cancer t-shirt is puce pink rather than grey or black or white, because they're trying to put a positive on a negative.’ (Linda)

Linda feels intense frustration with the superficiality of conversations with friends who are aware of her illness and who avoid asking about her health and discussing the challenges of living with her terminal condition. She further finds difficulty with others' use of euphemisms when speaking about terminal cancer in an effort to minimise the difficult reality of living with this disease. This leaves her feeling that she is unable to speak about her life with honesty and openness and to share her true feelings and worries. In this way, she is alienated and isolated in her emotional struggle and feels disconnected from those around her.

In summary, several participants experience emotional and physical detachment from certain family members and friends while living with terminal illness. In some cases, this feeling of being detached from others is due to participants' wishes to protect others from the reality of living with terminal cancer, while in other cases, it is due to the inability of others to have conversations about dying. This feeling of being detached from others results in emotional distress and feelings of alienation and isolation being experienced by participants.

5.6.2. Relating to other terminal cancer patients: 'They're the only ones who really get it'

While several participants speak about their difficulties with feeling emotionally detached from certain friends and family members, participants also highlight how helpful it has been for them to seek out and create connections with other patients who have received a similar diagnosis. Meeting and relating with others who share similar experiences helps participants to find support and comfort, while also helping them to find new meaning and purpose in their lives. Several participants describe how the creation of new friendships with other terminal cancer patients has been an integral aspect of living positively with terminal illness. The sense of understanding that exists among terminal cancer patients has enabled them to become more comfortable and to feel a sense of safety that they do not have with other people in their lives.

Layla speaks about her experience of spending time with other terminal cancer patients in the local cancer centre;

> ‘You could just go in [to cancer centre] and you wouldn't necessarily need to talk about cancer and the s*** that was going on, but you knew that you would be around people who knew, like they just knew what you were going through, and you could go and have a cup of tea. So, it was like a safety kind of place, you know just somewhere that you felt comfortable.’ (Layla)

Layla finds the local cancer centre to be a place of comfort and safety, where she can connect with others who share and can relate to her experience. She feels comfortable and safe in the presence of other cancer patients in the centre, who have a similar diagnosis and who understand her situation and to whom she doesn’t feel the need to explain about herself or the realities of living with her disease. They know from their own lived experience what it means to live with terminal disease. Spending time with others who share a similar experience helps Layla to feel at ease and to be herself in their company of others and this gives her a sense of wellbeing.

Evelyn also describes how she finds comfort in spending time with others who attend the same terminal cancer group as her and through her participation in a patient involvement group;

> ‘I get great comfort in the [terminal cancer patient group], because of some like-minded people, you know we're all sharing the same experiences. […] But definitely, between the [terminal cancer patient group], and my involvement from a patient perspective in [patient involvement group] and my family, they’re my reason to get up every morning, look after myself as best I can and nearly every day, I have something to look forward to, that involves one or the other. I live for all of that.’ (Evelyn)

Evelyn derives comfort from attending terminal cancer patient groups. These groups provide Evelyn with an opportunity to connect with other patients who speak about experiences that she can relate to during her terminal illness experience. Her involvement in these groups has helped her to find a new sense of purpose and reason for living each day, while looking forward towards the future.

Similarly, Adele describes how she attends her local cancer group and can relate to other terminal patients who are living with the same type and stage of cancer that she has;

> ‘I think a lot of people don't understand what you're going through, except other people with metastatic breast cancer. They’re the only ones who really get it. I think that's where that support from a group is so important. You can literally lay everything on the table and be truthful. […] [However,] when you are part of the group, especially with stage four, that group, the dynamics of the group change constantly. So, and what I mean by that is, you are seeing face to face, people in the group passing away, so that is always an

> eye opener. And it just kind of reminds you of the situation that you're in, even though you can skip on every day, and say, ‘oh look, I’m grand, I’m healthy, I feel very well.’ But, I've seen some of the girls in the group who are fine, healthy and well, and four weeks later, they're not with us anymore.’ (Adele)

For Adele, attending the terminal cancer patient group is a place where she can be herself, share her true feelings with others and feel understood by others who share a similar prognosis. This group provides her with emotional support and a strong connection with other terminal patients. However, being faced with the changing dynamic of the group serves as ‘an eye opener’ or a constant reminder of her own finitude. The awareness that other terminal cancer patients who she perceives ‘are fine, healthy and well’ may die suddenly, reminds her of the uncertainty of her life and prompts her to reflect on how unexpectedly her life could end.

Joanne talks about how she relates to other patients through sharing her terminal cancer experience with those who receive a similar diagnosis;

> ‘A lot of [other terminal cancer patients], they would often ring me up or they would come and just say to me ‘could I just ask you a little bit about this?’ So, when you've been on that journey of cancer and different things, and somebody is reaching out to you, and they're saying, you know, there's nobody I can ask about this.’ (Joanne)

Joanne uses the metaphor of a ‘journey’ to describe her experience of living with terminal cancer. She willingly connects with other newly diagnosed terminal cancer patients who ‘reach out' to her in their vulnerability to benefit from her sharing her experience of this journey with them. Through sharing her own cancer experience with others, she has found new meaning and purpose for being known and trusted by other newly diagnosed patients as someone who they can approach and confide in for advice and emotional support.

In a similar way, Ben speaks about how he enjoys sharing his story with other newly diagnosed patients;

> 'The only people who I talk about cancer with would be the other cancer patients. I share my story on social media. If somebody that knows me is diagnosed with cancer, they're straight on the phone to me looking for advice. Because I'm so positive about things. […] I have people from all over the world and I'm not exaggerating, following my story and I get messages often looking for advice and support. And that fulfils me actually at the moment. That helps me with my own.' (Ben)

Ben enjoys communicating with other cancer patients worldwide both on social media and by phone, who he provides support, positivity, and inspiration to, through sharing his own knowledge and experience of living with terminal cancer. Being widely known and trusted by newly diagnosed patients as someone who can advise and support them as they make sense of their new reality provides Ben with a sense of fulfilment and renewed purpose in life.

In summary, for these participants, spending time with other terminal cancer patients helps them to feel supported, comforted and understood. They have also found meaning and purpose in their lives as they share their own knowledge and experience with others who are living with terminal illness. The cancer centres and groups that participants attend are safe and relaxing places where they can be themselves, speak about their lives and feel accepted by those who they can relate to and who share a similar experience to them. Additionally, as cancer patients learn from each other and share their experiences with other terminal cancer patients, they feel more at ease in their own situation, and have increased wellbeing, while being acutely aware of their own finitude.

5.6.3. Cultivating meaningful relationships: 'My family, they're my reason to get up every morning'

While several participants describe how relationships with some family members and friends have become strained and, in some cases detached, other relationships in their lives have deepened as their circle of connections have become more refined. Participants speak about having a smaller number of more meaningful relationships in their lives and highlight how cultivating these valued relationships with family members and close friends is an integral aspect of how they live with terminal cancer.

Several participants describe how creating and maintaining meaningful connections and relationships with those who matter most in their lives helps them while living with their terminal diagnosis. Participants speak about how they value the important role that their families play in their lives.

Diana talks about how grateful she feels to have her family around her as she lives with her terminal condition;

> 'I was very lucky, like you know, to have your family. So many people had no family and my God, it must have been horrendous for them. You couldn't even talk to the neighbours you know. At least I had my family, so that was just great for me, when I think about so many others who had nobody. So that [relationship with family] just kept me going, I just really went with the flow to be honest with you. I think that's the way I cope.' (Diana)

Diana feels privileged and grateful to have the support that some other terminally ill patients may not have. Having family around her helps her to feel safeguarded and protected during difficult and challenging times. The valued support offered to her by trusted family members helps her to cope with the reality of living with terminal cancer each day. Her phrase of going 'with the flow' suggests that she lives day to day without worrying excessively about the future.

Similarly, Darragh describes how having the support of family members around him is hugely important;

> 'In terms of family, I have extraordinary support. Yeah, I cannot stress that enough. And I suppose I'm lucky in many respects, that I have a large family, and that I get on really, really well with all my siblings. […] Yeah, the support that I have is incredible. And is critically important to my well-being emotionally.' (Darragh)

For Darragh, having the support of his extended family is integral for his emotional wellbeing. He feels ‘lucky’ for the close connection that he shares with his family, and he has created and continues to maintain a strong relationship with each of his many family members. He recognises the significant value that having ‘extraordinary support’ from his family brings to his life and the positive impact it has on his wellbeing. The strength of this emotional support has a significant influence on how he copes while living with his terminal condition.

Ben also talks about his relationship with his son;

> ‘Spending time with my young fella. I absolutely love it. I do everything and anything with him. That’s the most important thing in my life. […] I live, sleep, breathe, eat, think, everything for him. We have a very close bond.’ (Ben)

For Ben, spending time with his son is now the most important aspect of his life. He loves and values the very close relationship that they share together. Through cultivating the ‘very close bond’ that he maintains with his son, he feels a significant sense of purpose and meaning in his life. Spending time with his son positively influences his wellbeing and feeling of happiness, despite living with terminal cancer.

Danielle describes her appreciation of having family and friends around her;

> ‘I've been very, very lucky with friends and family. I’ve been extremely lucky, so I’m thankful for all of that. You really learn to appreciate all of that far more when it’s

> threatened or when you say, ‘oh, I only have a few years left. Let’s enjoy them.’ (Danielle)

Danielle feels ‘very, very lucky’ with the friends and family that she has. She feels immense gratitude for the presence and support of these valued family members and friends. The knowledge of her finitude has deepened her appreciation of her close relationships and she wishes to enjoy her time left with the those who matter most in her life.

Layla also talks about feeling ‘lucky’ for having the support of her friends around her;

> ‘I have amazing friends. Yeah, I’m really, really lucky and blessed in that way. I've got a whole tribe of people that I can ask for anything. […] I’m hugely grateful to them. I think that they've helped in me still being here if I’m completely honest. I think having that positivity and energy around me has been huge.’ (Layla)

Layla feels ‘really, really lucky’ for having ‘amazing friends.’ She uses the metaphor of having a ‘whole tribe of people’ around her to describe her friendship group of like-minded individuals who have shared interests and who are willing to offer support to her. She feels immense gratitude for the emotional support and positivity she receives from these friends while living with terminal cancer and greatly values their presence in her life. She believes that the support gained through them has contributed towards her living a longer existence than she had expected.

Darragh speaks about how important his close friendships are to him;

> ‘In the last kind of three or four years we've re-established this really close friendship again. And we're now in almost daily contact with each other. […] So that's really, really important to me, but it's a different kind of support. It's a bit like Men's Sheds, the principle of Men's Shed where men stand side by side, because they won’t talk face to face. There's a little bit of that going on there. But there is definitely a huge feeling of their arms around my shoulder going, ‘you’re okay.’ (Darragh)

Following Darragh’s terminal diagnosis, his childhood friends that he had previously lost contact with, became once again more physically present in his life. Darragh highlights the proactivity of himself and others in cultivating meaningful relationships as they have been ‘re-established’ after being estranged from each other. These friendships have been further strengthened through renewed and regular contact with each member of the friendship group. Darragh alludes to ‘Men’s Sheds’ to describe how he communicates with his friends. ‘Men’s sheds’ are places where men get together to perform activities, where they don’t have to talk about their feelings, but where they ‘stand side by side together’ and gain support from others. While it’s not necessarily a form of communication, it is a feeling of togetherness with others. While this group of male friends provides significant support for him and a ‘huge feeling of their arms around my shoulder’ during his terminal cancer journey, they do not openly discuss the emotional aspects of his condition. However, their presence and the close bond that they maintain together bring him a strong sense of comfort, support, and increased wellbeing.

In summary, for these participants, having supportive and loving family and friends is an integral aspect of how they live with their disease. Being supported by those they trust most means that they have increased emotional wellbeing and can live life more fully.

In conclusion, navigating the social world is an integral aspect of living with terminal cancer, which can significantly influence participants' lives. When participants experience physical or emotional detachment from others following their diagnosis, they can feel emotional distress, as well as alienation and feelings of isolation. However, while some relationships may be lost or distanced, other relationships may be created or strengthened. Creating connections with other terminal cancer patients helps participants to feel supported, comforted and understood. The groups that participants attend are safe spaces, where they can be themselves, speak honestly and truthfully about how they are living their lives with terminal disease and where they feel accepted by those who share a similar experience to them. Cultivating valued relationships with close family members and friends brings participants purpose and meaning in life. Spending time with trusted and supportive loved ones and friends positively influences participants' wellbeing and feeling of happiness.

5.7. Journeying with Hope: '*Life is all about hope'*

As participants have lived with the reality of terminal cancer, some participants recall times when the physical and the emotional challenges became so overwhelming and immense, that they felt unable to live through and beyond them and they started *Losing Hope* in the possibility of their future. The intense feeling of isolation and alienation while living with terminal disease have also been a cause of feelings of hopelessness. While feelings of hopelessness were most acutely experienced by participants following diagnosis and treatment schedules, there are times when participants live with continued periods of hopelessness. Being given a short prognosis by health care professionals has resulted in one participant feeling continually hopeless for her future and feeling intense despair over the lack of possibility of outliving her prognosis. For most participants, however, the belief in *Finding Hope* has played a significant role in how they live their lives in a positive way, while living through periods of continued emotional and physical challenge. Participants speak about how *Living with Hope* can help them to move forward in times of challenge and despair and to live life with optimism, despite the uncertainty of the future. Through setting future based personal goals that they aim to achieve, participants create hope and positive expectation for themselves for a brighter and more positive future with meaning and optimism.

5.7.1. Losing hope: 'There is no hope, is there?'

Several participants began to lose hope in their future once they received their terminal cancer diagnosis. As these participants perceived that their future was uncertain and that their death was more imminent than once expected, they began to lose the sense of hope that was once present in their lives.

Evelyn speaks about how she felt hopeless at times while living with terminal disease;

> ‘There were days when I wanted to throw in the towel and I would actually just say, ‘I don't want to wake up in the morning, I’m ready, just take me now, I’m done.’ (Evelyn)

For Evelyn, living with continued physical symptoms and emotional distress became so difficult for her that she wished for her life to end. The metaphor of ‘throwing in the towel’ depicts how she felt hopeless for her future and felt ready for her life to end. She describes feeling ‘done’ with the situation as she struggled to come to terms with her terminal disease and the physical and emotional symptoms associated with it.

In a similar way, Layla recalls how hopeless she felt at times;

> ‘There have been times, especially in recent years, I’ve had a really tough maybe three years or so […] I was quite ill for a while, it came to the point where I felt that I just didn’t want to do it anymore. It was just too hard.’ (Layla)

For Layla, there were times while living with her disease, when the physical symptoms and the treatment side-effects became too difficult to cope with. The emotional and physical realities of terminal cancer that she experienced made it difficult for her to feel hopeful for her future as she struggled with having the will to continue to live her life. The continual emotional and physical struggle to live with terminal cancer had become so overwhelming for this participant that she lost hope in moving beyond these challenges and felt no interest to continue with her attempts to survive.

Adele also speaks about how she felt hopeless at times;

> “So, the isolation was huge as well, because I wasn’t sitting beside anybody with my story. So, there was no outlet for me to talk about it. And understand that there may be other people out there living with the same thing as me. I just thought I was on my own, the only person there living with this, and I thought, how long? How long am I gonna live for? Because there is nobody out there with stage four. So, I really thought from the very beginning that I was doomed really.’ (Adele)

Adele struggled with feelings of isolation and despair following her terminal diagnosis, which caused her to feel hopeless for her future. Her inability to find other terminal cancer patients and to hear about the experiences of others in a similar situation to her and how they continued to live with a terminal cancer diagnosis led her to believe ‘from the very beginning’ that she ‘was doomed.’ This sense of intense isolation, being ‘on my own, the only person,’ living with the despair of wondering ‘how long’ she would live for, left her feeling hopeless for the possibility of having a future.

Similarly, Linda talks about how hopeless she feels since receiving a terminal cancer diagnosis;

> ‘There is no hope, is there? […] But the thing is, if in January when I was given my diagnosis, someone had said to me, oh, you know, if you do a 5k walk or run every day,

> and if you eat a stick of broccoli or whatever, every day, you will extend your life, you'll double your life expectancy, or even miraculously, turn your situation around, I'd be out there, I'd be there in the tracksuit and trainers. I'm pretty sure that would give me the motivation that I needed. […] If someone tells you that doing something will make a difference, no matter how hard it might be, I would say 99.9% of people are going to grab that opportunity and say, do you know what, if it will make that difference it's worth doing. But if you're in a situation where you're basically told you're going to die anyway, it's not necessarily going to give you that enthusiasm to go out and do it. […] All the things that you thought you might like to do, and you're not gonna get to do them. And even if you do get to do them, you're not going to enjoy them. You're not going to experience them in the same way if you know you've got the 'Sword of Damocles' hanging over your head. […] [It's all] meaningless, and pointless.' (Linda)

For Linda, being given a short prognosis has resulted in her living with a loss of meaning in her life, and a loss of her perceived ability to live with hope and optimism for the future. This has negatively impacted upon her health and wellbeing as she no longer feels motivated to live a healthy life and no longer believes that engaging in healthy behaviours would be of any benefit to her due to her terminal disease. This loss of hope in the possibility of a future means that she does not find enjoyment or enthusiasm in her life as she's living it now and she has no expectation of finding happiness or meaning for her future. She uses the allusion of 'The Swords of Damocles' hanging over her head to describe how she lives with the knowledge that something bad could happen to her at any time. Due to her perceived inability to influence any positive change in her life expectancy, she no longer lives with hope or optimism for the time that she has left to live.

In summary, a sense of hopelessness was experienced by several participants. While this was most acutely experienced immediately following a terminal diagnosis and treatment schedules, there were also times when participants experienced emotional distress and despair and they felt hopeless for their future.

5.7.2. Finding hope: 'If you don't have hope, where is your future?'

Hope plays a central part in participants' lives as they live with terminal cancer. Several participants describe how finding hope, despite their terminal illness and short prognosis, has been a key factor in enabling them to live their lives with optimism.

Diana talks about how finding hope is an important part of how she lives with her terminal disease;

> 'Life is all about hope. […] I think hope gets you through a lot of things. You have to have hope, you have to believe. Whether it's something bad, you have to believe that it's going to get better. You have to believe that you can live through this cancer.' (Diana)

For Diana, finding a sense of hope is a way of dealing with difficult situations in life, such as how she has decided to live with the reality of having terminal cancer. Having a belief that life can be better than it is in moments of challenge and difficulty serves as a means of protecting herself emotionally and in looking towards the future with optimism.

Additionally, Darragh describes how he finds hope in difficult situations;

> ‘Hope, I am a great believer in hope. I am actually a huge believer in hope, despite man's own attempts to dash it every time he chooses to raise its head. It's really a simple concept in terms of, you know, wishing well for the future, hoping things will be better in the future or otherwise.’ (Darragh)

For Darragh, finding a sense of hope is a means of looking beyond the present difficulties that he is facing, and it enables him to look towards the future with optimism. When he finds hope in difficult situations, this enables him to live his life in a positive manner as he knows that present difficulties have a possibility of being improved in the future.

Similarly, Adele describes her belief in finding hope while living with terminal cancer;

> ‘I think hope is the one thing we really do hold onto, isn’t it? It's very, very important to have that hope. If you don’t have hope, where is your future?’ (Adele)

For Adele, finding hope is something to be cherished and valued as it is a key aspect of the possibility of having a future despite living with terminal cancer. She highlights that if she did not have hope, she would not know where her destiny would lie. By finding hope, she can look towards her future as she continues to live while dying.

Similarly for Joanne, she talks about what finding hope means to her while living with terminal illness;

> ‘Sure, we all have to move forward in hope. I mean, if you don't have hope, what else do you have? Because you know, when you have an illness, it's out of your hands. So, the only thing you could do is hope and pray that you are going to get to the other side of it. And I suppose hope is part of the positivity.’ (Joanne)

For Joanne, finding hope is a key aspect of living life with positivity, despite living with uncertainty and a lack of control over how her future might look. She emphasises the importance of finding hope, even in times of challenge such as illness, when there is uncertainty and when the future is ‘out of your hands.’ Finding hope within her difficult situation is a key to looking ahead and progressing forward within her life, despite the knowledge of her finitude. As she trusts in the power of hope and in prayer, she can look towards her future with optimism.

Layla describes how she balances finding hope with being realistic while she lives with terminal illness;

> ‘I think you need a balance, like I obviously have hopes for the future but I'm also realistic. I know there’s limitations.’ (Layla)

For Layla, having ‘a balance’ between finding hope and being realistic about her prognosis means that she can continue to live her life looking forward to her future while knowing the limitations of her condition and being able to come to terms with that. Finding this balance allows her to live well and look towards her future, despite her life limiting illness.

In summary, finding hope plays a central part in the lives of participants as they live with terminal cancer. Having hope plays a significant role in enabling them to live with their condition, to move beyond present difficulties and to find comfort in looking forward to better times ahead. As participants balance finding hope with having realistic expectation, they can navigate their way through their dark times and look towards the future with optimism.

5.7.3. Living with hope: ‘Hope never abandons you, you abandon it’

Participants’ belief in hope helps them to look beyond adversity and to move beyond their current difficulties and instead, to look towards the future with optimism. For several participants, hope is for a brighter future, despite living with the knowledge of a possible reduced life expectancy. Participants live with positive expectations for the future and create goals for themselves to achieve.

Danielle describes how living with hope helps her to live with terminal cancer;

> [Hope is] what’s keeping me going. Optimism, hope, yes, I hope that I’ll live for as long as possible and hope that I’ll have a good quality of life. That I’ll continue to enjoy life. Hope that I will maintain this attitude and that nothing will happen to change it. Hope is a big thing, […] yeah that would be the primary motivation. Instinct for survival, hope and optimism, whilst being realistic about my situation. But then, as I said, enjoy it and hope. Trusting your medical team is part of that hope. It’s all interlocked. None of these emotions or feelings stand alone, they’re all interlocked. For me, they are anyway. Nothing stands alone and they’re all interlocked. They all work in harmony to form a whole. They’re not disparate pieces of a jigsaw. Hope definitely is a great motivator. […] I think it's hope, belief and trust. […] It’s all of those things, not a single thing. It’s a whole lot of little things. They all mean something, one way or another. The main thing is hope and optimism.’ (Danielle)

For Danielle, hope is a primary motivating factor to help her to look forward towards the future, while also being realistic of her prognosis. Danielle equates hope with optimism and believes that each of these are necessary aspects of living life for as long as possible and for her quality of life. She continues to trust in her medical team, and this is an important aspect of living with hope and optimism for her. While having belief, trust, hope, and optimism are all facets of how she lives life, they are all inter- related and work together ‘in harmony to form a whole.’ Her belief in hope, as well as having trust and faith, helps her to continue to enjoy life and live with less worry or concern as her disease progresses.

Similarly, Kiera describes how living with hope helps her to live with her disease;

> ‘Hope never abandons you, you abandon it,’ […] Hope is something that you create for yourself and that's not always easy when you’re in the darkest place. But if you can find it in something, however small, it might be, ‘I hope I get out today for a walk, I hope I’ll feel better tomorrow.’ Yeah, it can be the smallest of things, or it can be something really big too, like ‘I hope I'll see next Christmas.’ Those are very real thoughts for somebody living in that position but it’s really important, even though it can be really hard to have it at times. It's really important to just get you out of the bed. You have to kind of cling to it, however unrealistic it might seem, you have to. What’s that other, ‘where there’s life, there’s hope.’ And that's true, there is, I mean I was down to my last few weeks and that's a lot to think about, but it’s better to be hopeful and looking forward than to be thinking about that too much anymore.’ (Kiera)

For Kiera, hope is something that she creates for herself to survive through times of despair and struggle, even when she is in the ‘darkest place.’ She lives with hope by consciously focusing on future milestones such as Christmas, or even simply persevering to see better days ahead. While living with hope can be challenging during times of difficulty, Kiera believes it is worth holding onto, ‘however unrealistic it might seem.’ Living with hope provides Kiera with the courage to live her life and look forward towards her future despite knowing that she has a terminal diagnosis, as it will never abandon her. This enables her to navigate her way through her darkest of times and to move forward with living life. By creating milestones for herself to aim for and to achieve, she has found ways to move forward while living with hope.

Evelyn talks about how she lives with hope for her future;

> ‘I was doing little things like that, little goals. And that was everything that I done. I just had little goals every day, little purposes and baby steps, stopping, looking further than when you wake up, what you had to do then. I done everything in little stages, so I always broke my day, and it all became about 9, 12, 3 and 6. I had to make sure something passed my lips at those times, even if it was only dunking a biscuit in a cup of tea. That's what I done, I just focused on that every time, if I had sips, but it had to be…to make sure it was a drink first and anything I could get past my mouth. I just kept building from there over time.’ (Evelyn)

Evelyn engages in setting small personal goals as a means of how she lives with hope for the future. By engaging in goal setting, she makes small manageable steps to help herself to keep going through times of challenge and to survive to see better days ahead. For this participant, setting small personal goals to reach on a daily basis has helped her to grow through and move beyond the significant difficulties that she was previously experiencing. Through this, she has found ways to live through times of challenge and to move forward towards the future.

Darragh talks about how living with hope helps him to live with terminal cancer;

> ‘So, the numbers say that my chances of living [5 years] after the diagnosis of metastatic sarcoma is 15%. My sarcoma has metastasized donkey's years ago, I suppose. Technically, you go 15%, which was actually a number of years ago. So, the sarcoma

> started to spread about 10 years ago. […] So, the chances of you still being alive with metastatic sarcoma after 10 years is teeny, teeny, teeny, teeny, tiny. So, I can logically say that somebody has to be it, you know, if you take hundreds to 1000s of people, and you apply even a 0.2%. Somebody has to be there, why not me?' (Darragh).

While Darragh had previously felt helpless, living with hope has enabled him to not give up, despite his poor prognosis. Having lived significantly beyond his prognosis, he believes that, even with this tiny chance of survival, he can continue to be alive, despite the statistical odds being completely against him. He believes that by living with hope and by keeping an optimistic outlook on his survival, he can live life longer than he had ever previously expected to.

Diana describes how living with hope helps her to live life with terminal cancer;

> 'Life wouldn't be worth living if there was no hope. You have to be hopeful, it's like talking about flowers, you plant something in the garden, and you hope it comes up, look forward to seeing it, if it does come up. But everything in life really is about hope. […] Hope is everything, when you look at it. […] Yeah, it is terribly important, you'd be terribly depressed all the time if you didn't have some hope, I think. Maybe we should stop and think and be grateful more often, you know that it is there. There's always hope, there's always light at the end of the road. Candles can be lit, the light will shine. It may not be you that's shining it, somebody else will shine it. It's there, it's there for all.' (Diana)

Diana believes that living with hope plays an essential part in living with positive expectation towards the future and looking beyond challenges and difficulties when living with terminal cancer. She uses the metaphor of planting flowers to suggest that hope is about looking towards the future with a bright outlook. She further uses metaphors of hope as both a light and a candle in people's lives to light the way forward and to brighten the darkness when dealing with difficult emotions. Hope allows her to live her life in a brighter and more meaningful way, which increases her sense of wellbeing.

Evelyn speaks about how she lives with hope for the future;

> 'Hope for me is… I keep looking into the future. Even though I say I live in the moment, with me, but hope is for changes in cancer. Hope is for survivorship. Hope is that it never visits anyone in my family, 'cause you know, when you've experienced it, you don't want anyone else to deal with it. Hope is for everyone that has to face this journey, for change.' (Evelyn)

Evelyn lives with the hope that although she is living with terminal cancer, others will not have the same struggles that she has and that things will change as time progresses. The concept of living with hope for Evelyn brings the possibility for change in the future for other terminal cancer patients, that they may have a more positive cancer journey than she is experiencing, such as changes in survivorship. She lives with the hope that anyone else who has to face this difficult journey will have a better experience than those who have gone before them.

In summary, living with hope helps several participants in this study to move beyond their terminal illness and current difficulties. It enables them to look towards the future with a sense of optimism, despite their poor prognosis. For several participants, hope is for a brighter future, despite living with the knowledge of a possible reduced life expectancy.

In conclusion, as participants lived with the reality of terminal cancer, the emotional and physical challenges for some participants became so overwhelming and challenging, they lost hope in the possibility of their future. While feelings of hopelessness were most acutely experienced following diagnosis and treatment schedules, there are times when participants live with continued periods of hopelessness. As participants adjusted to living with terminal illness, the belief in hope has played a significant role in how they live their lives. Living with hope can help participants to move forward in times of challenge and despair and to live life with optimism, despite the uncertainty of the future. Participants posited that hope gave them an appreciation of future possibilities that could come to pass while remaining cognisant of the limitations associated with their future. Further, through strategising and setting future based personal goals and milestones that they aim to achieve, participants create hope and positive expectation for themselves for a brighter future and to live with meaning and optimism.

5.8. Conclusion

In conclusion, in this chapter the researcher has outlined the findings of this study following analysis. Utilising an IPA approach, six themes were identified by the researcher. These include *Recovering Control in Uncertain Times, Gaining an Increased Awareness of*

Time, Negotiating a Changing Identity, Finding Comfort Through Connection, Navigating the Social World, and Journeying with Hope. The key findings of this study will be discussed within the context of existing literature in this area in the next chapter.

Chapter Six: Discussion

“Find a life worth enjoying; take risks; love deeply; have no regrets; and always, always have rebellious hope”

Dame Deborah James.

Chapter Six

Discussion

6.1. Introduction

The empirical study aimed to explore the lived experiences of individuals living with terminal cancer. The empirical findings offer a number of original contributions to literature as they illuminate and evoke rich insights into the experience of living with terminal cancer in an in-depth manner. The empirical findings highlight that the experience of living with terminal cancer is a multidimensional phenomenon and identify six core dimensions of this experience. Six themes were identified by the researcher following interpretative phenomenological analysis. These include *Recovering Control in Uncertain Times*, *Gaining an Increased Awareness of Time, Negotiating a Changing Identity, Finding Comfort Through Connection, Navigating the Social World,* and *Journeying with Hope,* each representing a different dimension within the experience of living with terminal cancer. While participants could not control their prognosis, they regained control over other aspects of their lives, despite the uncertainty of the future. As participants experienced existential angst, they viewed time differently and they focused on living well and leaving a legacy. Participants described navigating through a changing identity as they became a terminal cancer patient and grieved the lives that they once lived but also discovered other aspects of their identity. Participants found comfort through their relationships and cultivated meaningful connections which allowed them to live well. Participants posited that the terminal cancer experience reflected a dynamic journey with hope as while one may experience feelings of hopelessness, as they continued to live with terminal cancer, hope helped them to live well.

6.2. Recovering Control in Uncertain Times

The first group experiential theme identified in this study was *Recovering Control in Uncertain Times*. The sub-themes include spiralling out of control, regaining a sense of control and learning to live with uncertainty.

As participants in this study understood that their impending death was out of their control due to their terminal diagnosis, they began to lose control within their lives. Participants highlighted that this caused them to spiral into a cycle of distress which negatively impacted upon their quality of life. One participant in this study used a metaphor of "spiralling out of control" to describe her inner emotional turmoil following receiving her diagnosis with terminal cancer. Another participant's use of the metaphor of being suddenly "thrown into this world of the unknown" provides an insight into the emotional difficulty she experienced in trying to make sense of and come to terms with a new and uncertain situation in her life, which she perceived she had no control over. Another participant used the phrase "it really pulls your whole world around your ears" to describe her distress over the uncertainty of her future and her inability to influence the outcome of her disease. The lack of control over their lives and uncertainty over their future negatively impacted their wellbeing and quality of life.

These findings are similar to Lewis and colleagues (2019) who posited that individuals with terminal cancer associate a good quality of life with being able to maintain a sense of control in their lives, and that losing this sense of control results in a lack of dignity and lower quality of life for patients at the end of life. This lack of control that one may experience in the face of death while living with a terminal illness may contribute to increased spiritual distress due to the lack of meaning and purpose one feels while out of control of their own life (Kredentser & Chochinov, 2020). Further, the lack of control experienced by patients at end of life is associated with igniting a fear of the unknown and a feeling of loss in their lives, all of which exacerbate the emotional and existential distress that they may experience (Ford, 2016). The findings of this study reflect and build upon these former findings as they highlight the spiritual, emotional and existential distress that may be experienced by those specifically living with terminal cancer and that this distress may cause them to perceive that they are "spiralling out of control" at the end of life. In particular, the metaphors used by participants provide rich and deep insights into how living with uncertainty and a perceived loss of control can negatively impact their wellbeing and quality of life.

Participants highlighted that they felt vulnerable when they had to let medical professionals take care of their health rather than maintaining full control themselves. One participant used the phrase "throwing yourself at the mercy of somebody else" to describe her perceived lack of control over her own health and her vulnerability in surrendering control over her care to professionals. This phrase provides a deep insight into the significant emotional distress experienced by the participant over her perceived lack of control over her own care. Further, participants experienced vulnerability in surrendering their care to health professionals.

Their lack of knowledge and information about their disease highlights an imbalance of power and knowledge between participants and health professionals. This finding supports previous literature suggesting that while facing terminal illness, patients and their families face a great level of uncertainty and experience a lack of control due to the information asymmetry that exists between patients and medical professionals (Preston, 2015, as cited in Fitzgerald & Byrne, 2015). In the palliative care context, a core component of maintaining patient dignity is enabling them to maintain some sense of control over their own lives (Enes, 2003). Studies have shown that as patients are included within the decision making process about their care at end of life, they feel that they maintain a level of control and autonomy which empowers them (Lyon et al., 2004; Mo et al., 2012). The findings of this study suggest that participants' lack of knowledge and information about their disease negatively impacts their perceived ability to be an active participant in decision making over their care with healthcare professionals. The lack of control over their health negatively affects their wellbeing and is a cause of vulnerability and psychological distress.

The findings of this study suggest that an important part of the terminal cancer journey is regaining a sense of control and taking ownership of one's life. While participants in this study understood that there were elements of their lives that they could not control such as their terminal diagnosis or impending death, they attempted to control other aspects of their lives such as their health and managing their symptoms so they could live well. The health locus of control theory (Wallston & Strudler, 1982), which was developed from social learning theory (Rotter, 1954) may be used to help us to understand and make sense of these findings. Health locus of control (HLoC) refers to the belief that individuals possess an internal (being in control) or external control (locating control outside of oneself, either in others or chance) over their own physical and mental well-being (Nazareth, 2016). External HLoC consists of two dimensions specifically, powerful others implying that health related outcomes are related to powerful others in one’s life such as doctors, and chance referring to health outcomes being related to one’s fate (Levenson, 1972; Grotz et al., 2011). HLoC plays a significant role in shaping the health behaviours within a given population (Pourhoseinzadeh et al., 2017). Adults who have an external locus of control tend to have poorer health outcomes than those who have an internal locus of control (Gale et al., 2008; Nazareth, 2016; Kesavayuth et al., 2020). However, literature examining one’s locus of control in the context of terminal illness suggests that those who maintain a high level of internal HLoC may be at risk of experiencing decreased levels of physical and mental wellbeing at end of life as their level of control may be impacted by external or contextual factors within their lives related to their health status (Brown et al., 2017).

The findings of the current study do not necessarily reflect these former results as patients who took part in this research highlighted the importance of maintaining their internal HLoC and they played an important role within the decision making process regarding their care. These findings suggest that, while patients did trust and listen to their oncologists, those in the terminal phase of their disease desire to maintain a higher internal HLoC (therefore not leaving things to chance or powerful others) than those with cancer that responds to curative treatment. The experience of participants in this study suggests that terminally ill cancer patients seek control over as many aspects of their lives as possible in a context where they have very little control over their own lives. Hence, this study contributes to existing theory by highlighting that one’s desire for control may be intensified following the receipt of a terminal diagnosis, specifically in the context of cancer.

The findings of this study also suggest that the desire to take control from the perspective of terminal cancer patients encourages them to develop strategies to manage their own health. For example, one participant in this study described how he built a “bespoke” support system around himself, that was specifically tailored to his unique needs and specifications. Other participants in this study gained a sense of control over various aspects of their lives such as managing their diet, or attending workshops to gain tools to emotionally cope with terminal cancer and to educate themselves about their illness to make informed decisions. In this way, participants found they could successfully take control of their lives and manage the uncertainty of their illness. The strategies used by participants in this study to take control over their health builds upon previous literature in self-management. In the context of terminal or advanced cancer specifically, according to Hughes and colleagues (2016), self-management refers to the behaviours that individuals perform to try and relieve, minimise or prevent pain in an attempt to cope with their illness (van Dongen et al., 2020). Self-management in patients with cancer has previously been studied within the psycho-oncology literature (Gao & Yuan, 2011; McCorkle et al., 2011; Cuthbert et al., 2019). While the concept of self-management has been widely studied in the context of chronic diseases (Bodenheimer et al., 2002; Sevick et al., 2007; Lerch & Thrane, 2019), recent advances in this area have focused upon those living with advanced cancer (Budhwani et al., 2019; van Dongen et al., 2020). Existing studies suggest that, in the context of advanced cancer, self-management practices are effective in managing pain and fatigue (Chan et al., 2016; Azizoddin et al., 2021). Additionally, Noorlandt and colleagues (2022) posited that, while those with advanced cancer often experience self-management challenges, they may also develop self-management strategies aiming to maintain a sense of normality within their lives. The findings of this study confirm self-management is also an important topic to consider within the context of terminal cancer patients specifically, as many participants in this study developed their own self-management strategies that enabled them to live well with their illness. As participants developed their own self-management strategies to cope with their illness, they regained a sense of control within their lives as they dictated how they would live their lives in relation to their terminal illness.

Participants in this study reported that a key factor in enabling them to restore some level of control within their lives was educating themselves with the appropriate knowledge to make important decisions regarding their treatment and care. In this study, participants perceived that they could only advocate for themselves when they had the knowledge to do so and this led to them feeling empowered. Indeed, patient education and effective self-management are related as, when patients are provided with knowledge, they can then make better decisions regarding their own health and have the confidence to do so (Bennett et al., 2009; Jarvis et al., 2010; Marie et al., 2013). Evidence from other contexts suggests that patient-centered interventions are needed to empower patients to self-manage and coordinate their own care in accordance with their individual needs (Lovell et al., 2014). The majority of patients in this study highlighted that they had to seek out the support groups and programmes within their respective communities and care settings where they learned from other patients' experiences through tacit knowledge transfer rather than having formal patient educational interventions. These findings support those of Chio and colleagues (2008) who highlighted that peer-support was a significant resource in the lives of terminal cancer patients and helped them to overcome spiritual suffering at end of life. Through listening and learning from the experiences of others, participants in this study highlighted that they could live their lives well and regain a sense of control over their own lives. The findings of this study suggest that peer-led patient education programmes may help patients to regain a sense of control in their own lives by providing them with the knowledge to engage in the development of self-management strategies that they can implement within their own lives to help them live with the uncertainty that they are experiencing due to their terminal disease.

Participants in this study highlighted that taking back some level of control within their lives facilitated them in learning to live with the uncertainty associated with their terminal cancer. As participants regained a sense of control and developed coping strategies, they could effectively adapt to their ‘new normal’ and learn to live well with their illness. Many participants identified that this change of mindset allowed them to reframe how they lived with their disease and that while the illness did not go away, that it did not limit how they lived their lives. One participant referred to the experience of living with terminal illness as a ‘whirlwind’ that never went away but that she learned to handle over time. This metaphor offers insight into the experience of living with terminal cancer and the process of losing and gaining control in this context. Participants highlighted that they could control their mindset and that by not dwelling on things that they could not control, living with their disease became less intimidating and living well became possible again. Research has shown that the perspective of patients with terminal illness is likely to shape their actions, behaviour and experiences (Spichiger, 2006). Many participants in this study reported changing their perspective and expectations of their lives by relinquishing control to gain advantage in their lives. While sacrificing control and trusting in a higher power at the end of life has been cited within existing literature (Nakashima & Canda, 2005; Cole, 2005) as resulting in positive outcomes for patients, the findings of this study do not completely support these findings.

The findings of this study somewhat differ from existing studies as participants did not report sacrificing the sense of control that they had in their lives, but acknowledged that their sense of control was limited to a certain extent. These findings relate to existing literature focusing on the Heideggerian ‘call to conscience’ where one’s awareness of death brings one into an awareness of finite possibilities based upon the context that one is in and causes one to feel a sense of guilt for not acting upon these possibilities (Wickler, 2016). While the idea of a ‘call to conscience’ and the awareness of finite possibilities did arise for participants in this study, participants did not report having a sense of guilt for not acting upon them. Rather, the findings of this study suggest that terminal cancer patients may become aware of the range of limited possibilities in front of them due to their terminal diagnosis and do not want to surrender to external forces such as powerful others or chance due to guilt for not being able to fulfil their potential and hence, insist on being able to choose their own way and maintain some level of control in their life.

6.3. Gaining an Increased Awareness of Time

A second group experiential theme identified in this study was Gaining an Increased Awareness of Time. The sub-themes include feeling existential angst, valuing time as currency, living on borrowed time and leaving a legacy.

In this study, participants gained an increased awareness of the passage of time following their terminal diagnosis. In several cases, participants reported experiencing a hyper-awareness of, and preoccupation with, time. This increased consciousness of time led to participants reflecting upon the temporality of life and how much time they might have left to live their lives. Nielsen and Skotnicki (2019) posited that human experience by its very nature is temporal, and that gaining a further understanding of the concept of time may help us to understand social patterns, behaviours and transformations. Heidegger (1927) referred to temporality as being 'ecstatically unified' as both the past and the future are united in the present and each of these three dimensions of time contribute to lived experience (Stolorow, 2003). Additionally, Heidegger contended that, in contrast to philosophical convention, time derives its significance in death rather than in eternity (Alweiss, 2002). Being towards death, according to Heidegger, offers several key insights, specifically, death is certain, own-most, indefinite and not to be outstripped (Foulds, 2014; Dreyfus, 1990). According to Heidegger's insights, death is individualised and is a core part of Dasein or one's being, as one is stripped of their supports and relations (Blattner, 2006). Heidegger's insights help us to make sense of and understand the findings of this study. The findings highlight how participants experienced their mortality in terms of Heidegger's key insights of being certain, non-relational, own-most, indefinite and not to be outstripped. As participants were faced with their death, they experienced existential distress and worry over the awareness of their impending death. This was experienced most intensely when participants were alone, in the silence and darkness of the night time hours. Participants in this study confronted their impending death and the uncertainty of time left in their own way and experienced existential anxiety when they had to face their mortality within themselves.

The findings of this study in relation to time indicate that participants experienced significant existential, spiritual and emotional distress caused by the knowledge of their terminal cancer diagnosis. These findings mirror previous literature demonstrating how living with terminal cancer can initiate significant psychological, social, spiritual and existential distress for individuals (Austin et al., 2011; Tang et al., 2014; Julião et al., 2013; Güell et al., 2015). These types of distress may be regarded as different dimensions of suffering in individuals (Ellis et al., 2015). The findings of this study highlight how participants lived with periods of intense worry and concern about their finitude and experienced death anxiety. Some participants of this study used metaphors to describe their experience of death anxiety. Metaphors which were used include the 'ticking of a clock,' 'loud ticking noise in the back of your head,' 'drowning,' 'little voice' that 'whispers quietly,' and 'cold fingers on your shoulder.' These metaphors provide valuable insights into explaining the depth of emotional distress caused by death anxiety that was experienced by participants living with terminal cancer. Death anxiety has been defined as "the state in which an individual experiences apprehension, worry or fear related to death and dying" (Carpenito-Moyet, 2008, p.39). Death anxiety has been further referred to as a "vague uneasy feeling of discomfort or dread generated by perceptions of a real or imagined threat to one's existence" (Moorhead et al., 2008, p.761). The findings of this study mirror previous literature which has indicated that death anxiety may be triggered by one's increased awareness of their mortality, such as following the diagnosis of a life threatening illness (Lehto & Stein, 2009; Neel et al., 2015). The findings also build upon recent literature which suggested that death anxiety resulted in psychological distress, depression, and reduced quality of life in patients living with terminal illness (Sherman et al., 2010). The metaphors used by participants in this study to describe their experience of existential angst and death anxiety following their terminal diagnosis were particularly insightful and contribute to literature as they provide additional insights into and a deeper understanding of the experience for individuals living with terminal cancer specifically.

The findings of this study in relation to this theme also highlight the intense spiritual distress and existential struggle that participants faced as they attempted to make sense of their diagnosis and come to terms with their finitude. Although this distress was experienced most acutely in the initial period following a terminal diagnosis, participants lived with continued periods of emotional struggle, despair and loss of meaning. While the physical needs of participants of this study were addressed, many participants reported how they perceived that they did not receive adequate support to meet their psychological, spiritual and existential needs. This contributed to their suffering and spiritual distress and negatively impacted their quality of life. It has been well documented in literature that the healthcare system requires consideration of not only the biological and psychosocial needs of patients at end of life, but also their spiritual needs (Connor et al., 2002). Spiritual distress relates to the spiritual and existential dimensions of one's being and, according to Anandarajah & Hight, (2001, p.83) may "occur when individuals are unable to find sources of meaning, hope, love, peace, comfort, strength and connection in life or when conflict occurs between their beliefs and what is happening in their life." The findings of this study reflect previous literature and provide further insight into how spiritual distress may result in reduced quality of life, feelings of despair, meaninglessness and suffering.

The findings of this study in relation to this theme indicate that an increased awareness of time may also have a positive impact on the lives of individuals living with terminal cancer, despite the existential angst that they may be experiencing. Participants gained an insight into how valuable time was as they lived with terminal disease. Time was perceived as a valuable currency and an important commodity in the lives of participants as they prioritised who and what truly mattered at this time of life. The findings of this study also demonstrate how one's beliefs and values may shift as one lives with terminal cancer. Participants in this study reported that while before their diagnosis they had valued material goods such as cars or other extrinsic factors such as their career development, following their terminal diagnosis they began to value the simple things in life and, most importantly, the time that they had left to live their lives. These findings build upon previous literature which identified that when faced with their own mortality, people were likely to shift towards intrinsic values rather than extrinsic values (Cozzolino et al., 2009, Lykins et al., 2007; Prentice et al., 2018). The findings further our understanding of how the changes in one's awareness of time may positively impact how one lives with terminal cancer and may influence one to re-evaluate one's beliefs and values.

Further, the findings of this study in relation to time highlight how for participants who outlived their prognosis, each additional day that participants lived was perceived as a gift and a blessing. Despite all participants knowing that their prognosis was less than a year as they lived with terminal cancer, the unexpected and much appreciated gift of additional time offered them the opportunity to live their lives as they wished to. Participants chose to live their lives on a daily basis according to their own wishes and in ways that they could maximise their own wellbeing and quality of life. According to Heidegger's philosophy, death has the potential to provide an orientation or perspective for one's authentic temporal understanding (Chanter, 2001). Heidegger posited that it is only when one is faced with one's death, that one can live a meaningful and authentic existence as genuine existence is only when one faces one's death, and one's life is, by its nature, being-towards-death (Grene, 1952; Edwards, 1976). This may be contrasted with what Heidegger refers to as an 'inauthentic positioning towards death,' where even after the diagnosis of a life limiting disease, one continues with the everydayness of life, through repression and denial of death (Gullick & West, 2020). The findings of this study aligned with Heidegger's authentic positioning towards death, as participants accepted their mortality and experienced increased appreciation of life and the possibilities that were available to them, and lived with authenticity, meaning and purpose.

These findings support those within existing literature as living life in the present is a commonly cited theme within literature examining the perspectives of patients at end of life as patients attempt to attain a sense of normality in their lives (Lee & Ramaswamy, 2020; Lormans et al., 2021). However, the participants in this study not only expressed a desire for normality but also a desire to live well during this time in their lives. Participants who remained grateful for the time they had left maintained a positive attitude towards living life, despite their poor prognosis. These findings are similar to those reported in studies from other contexts such as patients living with Parkinson's disease as a meta-ethnography of qualitative studies suggests that maintaining a sense of gratitude enabled participants to live life in the face of their disease (Wieringa et al., 2022). This is further elaborated upon in the context of terminal illness by Englund (2022) who highlighted that gratitude and gratefulness may help one to come to terms with one's illness and ill body without becoming defined by one’s illness. The findings of this study provide a valuable insight into how, when one faces one’s mortality, one may live with an authentic existence and appreciation of life and live with increased meaning and purpose. Additionally, these findings add to previous research by highlighting how living with gratitude may help individuals to live with increased positivity, despite having a poor prognosis. These findings contribute to our understanding of how individuals may live well with terminal cancer.

The findings of this study suggest that the time participants had following their diagnosis was used to engage in self-reflection on the life that they had lived, for self-compassion and for personal growth. Participants were acutely aware that their time was limited but also recognised what they had achieved in their lives to that point. Several participants reported how they wished to use the time that they had left as an opportunity for personal growth, despite their terminal condition. The experience of terminal cancer and illness has been highlighted in literature as a ‘turbulent’ experience of managing disruptive events that cause biographical disruption in the lives of those affected (Reeve et al., 2010). While it is acknowledged that the cancer experience may cause post-traumatic stress, literature suggests that it is also possible to grow through the experience of cancer (Jim & Jacobsen, 2008). The findings of this study reflect this previous literature as they highlight how, while living with terminal cancer, participants consciously may use their time to engage in self-reflection, personal growth and self-compassion. Within health and clinical psychology literature, the experience of cancer has been studied in the context of growth post-trauma (Cordova et al., 2007; Connerty & Knott, 2013; Parikh et al., 2015). A recent systematic review and meta-analysis conducted by Marziliano and colleagues (2020) highlighted that there is evidence to suggest that advanced cancer is more associated with growth than those with a low-grade tumour. The findings of this study suggest that these findings are also applicable in the context of terminal cancer patients who are living with an incurable disease, as many participants reported how they used the time they had following their diagnosis to engage in self-reflection, self-compassion and personal growth. Further, Pargament and colleagues (2014) highlighted that spirituality may be a source of positive growth during difficult times such as in the face of illness. The findings of the current study further our understanding of personal growth during the terminal cancer experience as they suggests that participants may use this time left to engage in self-reflection, self-compassion and growth, even in the face of their illness.

The findings of this study highlight the concerns of several participants living with terminal cancer about how they would be remembered by others after they have died. Participants wished to leave behind a legacy of inspiring others beyond their death and enabling others to learn from their experience of how they lived their lives. Participants wished to be remembered as an inspiration to others to be fearless in life, to live with purpose and meaning, undertake new challenges, and engage in self growth. In essence, each of the participants wished to leave a positive impact on the world and this enabled them to live with peace in the knowledge that they lived a life of value, meaning and purpose.

These findings correspond with a ‘legacy typology’ which was developed by Hunter and Rowles (2005, p.327). According to this model, legacy may be characterised in three forms, namely biological, material and values. The findings of this study align with this model as some participants considered their children and grandchildren as their legacy. Notably, only one participant of this study indicated that his legacy would include the donation of his material wealth. The findings of this study also concur with the ‘legacy typology’ model in terms of values (Hunter & Rowles, 2005), as participants inspired others with their life stories, fearless mindsets, undertaking new challenges and engagement in self growth. Participants shared their personal beliefs of the power of hope and optimism to inspire others to persevere through times of adversity and challenge and to live well in the face of dying. The findings of this study further our understanding of legacy as participants strove to leave behind a positive impact on the world, in terms of helping others and inspiring others, despite living with terminal cancer. The use of the legacy typology model helps to extend our knowledge about legacy in the terminal cancer experience as the findings provide an insight into how legacy may represent an extension of one’s existence beyond one’s lifetime.

The findings of this study in relation to time mirror previous literature on leaving a legacy, which highlight how creating a legacy represents core personal values and how a legacy exists beyond one’s life. These findings mirror those of Coyle’s (2006) study which indicated that while legacy included leaving a physical legacy, such as money, it also represented a bridge between existence and non-existence, where individuals may be remembered beyond their lifetime for their value and contribution in life. The findings of a systematic review conducted by Boles and Jones (2021) indicate the therapeutic value of introducing legacy interventions for individuals living with terminal cancer in terms of psychosocial and spiritual wellbeing, preparedness for end of life, meaning and peace. The findings of this study provide additional insight and understanding of the importance of leaving a legacy for terminal cancer patients in terms of recognising and valuing one’s unique contribution to the world and the positive impact their lives had on others. Further, the findings extend our knowledge on legacy in the terminal cancer experience, as they provide an insight into how legacy represents an extension of one's existence beyond one's lifetime.

6.4. Navigating a Changing Identity

A third group experiential theme identified in this study was *Navigating a Changing Identity*. The sub-themes include becoming the terminal cancer patient, shifting between past and present identities and re-defining oneself.

The findings of this study suggest that finding oneself as a terminal cancer patient represented an overwhelming life transition for each participant, which had a significant impact on their identity. Participants reported feeling overwhelmed by this new aspect of their identity that they had little control over, as they found themselves undergoing treatment for their disease. The concept of illness may help us to understand the impact that terminal cancer may have on one's identity. Illness behaviour can be defined as "the way in which symptoms are perceived, evaluated and acted upon by a person who recognizes some pain, discomfort or other signs of organic malfunction" (Mechanic & Volkart, 1961, p.52). Further, Suchman (1965) proposed five key stages of illness behaviour representing transition points within the experience of illness which include the symptom experience stage, the assumption of the sick role, the medical care contact stage, the dependent-patient role stage and the recovery stage of illness. At the time of interviewing, participants in this study were specifically at the dependent-patient role stage, where they had become a patient and had experienced the ambivalence associated with the adjustment to this role, but had not progressed to the recovery stage, due to the terminal nature of their disease (Suchman, 1965). The findings in this study differ from those outlined by Suchman (1965), as participants in this study found it increasingly difficult to adjust to identifying themselves a patient due to their terminal diagnosis as they knew that this stage was not a temporary phase between illness and returning to health as with other illnesses, but rather a permanent state due to their terminal condition. While literature suggests that other cancer patients and their loved ones may focus on adopting and embracing the identity of becoming 'cancer survivors' following their course of treatment, rather than seeing themselves as a patient (Park et al., 2009; Miller & Caughlin, 2013; Cheung & Delfabbro, 2016), this may not be the case for terminally ill patients highlighting that becoming a 'terminal cancer patient' may be a unique experience in and of itself due to the fact that patients are aware that they will never be free of their disease due to its terminal nature.

Participants in this study also reported that their diagnosis of terminal cancer influenced how they perceived themselves and how others perceived them. They felt that it was difficult to live their lives while being branded or labelled as the 'terminal cancer patient.' Labelling theory (Becker, 1963) and later developments and modifications of this theory in the context of mental illness by Scheff (1974) and Link and colleagues (1989) posit that the behaviour of individuals and their self-concept and identity may be influenced or affected by the given social or cultural conceptions that may be used to describe them (Kroska & Harkness, 2006). While traditionally labelling in the context of health may have been seen as beneficial in terms of diagnosis and treatment, it may also have a detrimental impact on one's ability to cope with their illness (Link & Phelan, 1999). Further, Link and colleagues (1989) highlighted that, while labelling itself is not responsible for the mental disorders that people face, individuals with mental disorders may face negative outcomes such as discrimination or devaluation due to the stigma that they may face within their social environment. The findings of this study suggest that these consequences within one's social world and the impact this has on one's identity is also relevant in the context of terminal illness. Participants in this study highlighted that their social world became difficult to navigate within as their relationships began to change as some acquaintances began to distance themselves as they saw participants as a 'cancer patient.'

Additionally, participants in this study highlighted that they found that it was immensely difficult to maintain aspects of their identity that they had valued pre-diagnosis as their terminal disease changed their ability to maintain social roles such as their work or familial roles. This resonates with the findings of research by Mathieson and Stam (1995) who highlighted that the experience of cancer often required individuals to renegotiate their own identities as they experienced a sense of disruption or misfit between their identities and their experience of illness. This situation is generally reflected within the oncology literature as the experience of cancer is often not conducive to individuals living their lives in a normal way due to the disruption they experience to their physical and psychological functioning as well as their social lives (Lang et al., 2013; Polanski et al., 2016). It is also common for cancer patients to be concerned about fulfilling their social roles, despite the difficulties that they may face in doing so (Fang et al., 2011; Lavdaniti & Tsitsis, 2015). In this study, participants reported that they felt that they had no purpose when they were unable to go to work and make a meaningful contribution to society. A similar conclusion was reached by Rasmussen and Elverdam (2008) who suggested that cancer patients who are unable to work lose a significant part in their identity associated with their occupation. Additionally, studies suggest that work plays an important role in the lives of those living with cancer as it provides them with a sense of purpose, restores a sense of normality in their lives and allows them to restore their sense of identity (Rasmussen & Elverdam, 2008; Wells et al., 2013). However, when comparing the results of this study with those of former studies, it is important to highlight that, while participants highlighted that they were concerned about fulfilling their social roles, they maintained an awareness that some of these social roles were not recoverable in their lives due to their terminal condition. By virtue of their incurable and terminal condition, the findings of this study highlight the specific lack of purpose experienced by terminal cancer patients as several participants in this study were unable to maintain their former roles and return to work and had no possibility of doing so either. Hence, these participants experienced some level of job change and career mobility. The results of this study highlight the unique nature of the terminal cancer experience due to the additional loss that participants felt they had experienced due to their illness. This experience is unique as these roles are not recoverable in the context of living with terminal illness. Hence, the loss of their jobs resulted in significant changes in their own identity and they lacked the sense of purpose that they once got from their working roles. This loss contributed to participants' grief of the lives that they once had lived.

Participants in this study expressed that they experienced grief of their former lives and the roles they had previously played in the context of their family lives. The participants struggled in becoming a terminal cancer patient as this meant that they had to resign from their former role as a caretaker for those around them and accept that they had to be cared for. One of the most prominent concerns for patients living with terminal cancer is their family and their ability to care for those around them (Kelly et al., 2002; Cao et al., 2020). This concern is mirrored in the results of this study as participants felt that it was their role and responsibility to care for those around them and they struggled to accept their situation when these roles were reversed following their terminal cancer diagnosis. Additionally, studies have shown that a significant concern of patients living with terminal illness is that they do not want to be a burden on family members as they become more dependent on them (Kelly et al., 2002; Johnson et al., 2007; Chochinov et al., 2007). While participants in this study were not immediately concerned about becoming a burden on their family, they did report that they feared that someone else would not be able to fulfil their responsibilities or to care for their loved ones in the same way that they would be able to. Hence, they grieved their former lives when they were able to live independently and missed being able to be there for their loved ones in the ways that they traditionally had been.

Further, participants in this study grieved their 'old self' and the life that they once lived. Participants felt that they missed their old self beyond the social roles that they had maintained as they felt a loss of 'self.' While existing literature in the area of cancer focusing on the loss of identity and self-concept refers to the physical aspects of the illness such as the loss of one's hair or body image disturbance (Helms et al., 2008; Przezdziecki et al., 2013), it is important to consider the loss of one's sense of self beyond the physical dimension. Bury (1982) identified chronic illness as a 'biographical disruption' in an individual's life. This disruption requires the person to re-evaluate their self-image and how they live their life and mobilise resources to deal with the changes which are brought on by the illness. It also involves undermining their assumed beliefs about their concept of self and their health (Charmaz & Belgrave, 2013). Reeve and colleagues' (2010) study found that terminal cancer patients may also experience biographical disruption in their lives as they live with their illness. The findings of the current study support these former results as participants also highlight their loss of sense of self and identity while living with terminal cancer.

Participants in this study reported that they felt a sense of loss due to their inability to live their lives in line with the plans they had made for their own future. They reported that their own hopes and dreams were lost and they now had to take a more ‘realistic’ approach to living their life as they are aware of their poor prognosis. Despite this, participants found it difficult to grieve or convey their emotions to others as they felt that they would be a burden and wanted to protect others. It is important to acknowledge that grief is a subjective phenomenon and individuals may grieve at the subsequent losses that they experience due to cancer (Doka & Martin, 2014). However, as individuals' plans or dreams are individually constructed, the findings of this research suggest that participants may be experiencing disenfranchised grief. Disenfranchised grief is defined by Doka (1999, p.37) as “the grief experienced by those who incur a loss that is not, or cannot be, openly acknowledged, publicly mourned or socially supported.” This type of grief may be experienced by individuals as feeling as if they do not have the right to grieve (Doka, 2002). Participants in this study express this sense of dissonance rooted in disenfranchised grief as they feel while living with terminal cancer as they grieve the lives they once lived but conversely feel that they have no right to grieve as they are lucky for each day they now have. Participants in this study reported that they felt that they had to live the rest of their lives in as best a way as possible for those around them and hence, could not truly acknowledge how they felt to others. This caused them to grieve their old selves in private when they felt they could acknowledge their own feelings without the worry of unintended consequences on others.

The findings of this research in relation to identity suggest that the experience of terminal cancer enabled participants to discover aspects of themselves that they had previously been unaware of. This helped participants to adapt to living life with their terminal illness and to embrace their sense of self, in contrast with the other findings highlighting that one may lose their sense of self. These findings shine a light on how one must be willing to shed some aspects of one's former sense of self to experience a change and embrace other aspects of one's true sense of self, and allow both of these selves to co-exist within their life. These findings are supported by previous literature which highlight how living with illness initiates changes in self as individuals adapt and find new ways of living. Charmaz (1995) posited that living with serious and chronic illness causes a disruption in the unity of mind and body and forces changes in an individual's sense of self and identity. Further, Charmaz (2002) maintained that serious illness necessitates a re-construction of self through changes in one's habits of thinking, feeling and acting and it initiates changes in one's priorities as they adapt to a new way of living. Additionally, Frank (2002) posited that living with a life threatening illness brings individuals to the threshold of their life where they are faced with the possibility of death. From this perspective, an individual is both forced and also enabled to think about how they value life and how they live their life and to consider new ways of living. Frank (2002) further maintained that, while illness involves loss of some aspects of life, it also provides an opportunity for an individual to choose how one wishes to live out the rest of their life. In his view, even the experience of dying offers an opportunity for renewal of how one lives their life, despite experiencing loss. The findings of the current study support these findings in the context of those living with terminal cancer as this experience enabled some participants to discover aspects of themselves such as a sense of strength and confidence which they had not been aware of before their diagnosis while they also lost some other aspects of their identity.

The findings of the current study in relation to identity highlight that, as one discovers new aspects of oneself, one can live with new meaning and purpose despite one's terminal illness. Victor Frankl (1953) posited that suffering is an eradicable part of life that humans experience. Further, he also put forward the idea that suffering can be meaningful and can promote a sense of 'wholeness' and wellbeing in terminally ill patients (Frankl, 1953; Chidwick, 1988; Wiebe, 2014). Through suffering, one gains the capability to turn situations that may be perceived as hopeful into achievements when one overcomes suffering and pain (Schimmoeller & Rothhaar, 2021). Periods of stress or turmoil may result in positive psychological transformation for those who experienced the trauma (Taylor, 2017). The experience of suffering highlighted by participants in this study enabled them to find new meaning in their lives such as when one participant left her job and returned to education for self-development purposes. This suffering and development impacted upon their sense of self as they found a new sense of purpose in their lives. These findings correspond with those of Ellis and colleagues (2015) who highlighted that those living with advanced cancer experience unavoidable suffering due to their progressive disease but despite this, patients utilised spirituality as a lens to view the world which enabled this experience to transform the way that they lived their lives and develop a more coherent sense of self. These findings are reflected in this study as participants reported that they were enjoying their lives in ways that they had never before and were able to be a more authentic version of themselves.

In this study, participants highlighted that they were able to experience a greater sense of harmony within themselves following the discovery of new aspects of themselves that they were previously unaware of. They suggested that this enabled them to live their lives in a more meaningful way. Authenticity has been highlighted as one of the key values of existentialist philosophy and has been written about by several philosophers including Heidegger, Nietzsche and Camus (Nietzsche, 1887; Heidegger, 1927; Camus, 1942; Golomb, 1995). Traditionally, according to existential philosopher Nietzsche, one can only be truly fulfilled and embrace their authentic selves when one lives in line with one’s own judgement, which was not possible when living in a world that was driven by religious morality, according to Nietzsche (Meynell, 1995). Hence, his view proposed that it is morally good to live life as though moral goodness did not exist at all and he rejected formal religion (Meynell, 1995; Fraser, 2013). Similarly, Heidegger interpreted authenticity as “choosing the nature of one’s existence and identity” (Yacobi, 2012, p.28). Heidegger (1927) posited that one cannot be limited by moral rules and pre-existing norms if they are living authentically and autonomously, and that that this is a choice at the ontological level that one must make (Heidegger, 1927; Philipse, 2021). Further, according to Camus, authenticity is only true if it remains true to act that it rises from (Neiman, 2017). This idea of authenticity goes beyond rational discourse and desires to create unity, clarity and cohesion within one’s life (Golomb, 1994). The findings of this study reflect the traditional philosophical views on authenticity as participants highlight that they experienced a greater sense of harmony within themselves and could live their lives in a more meaningful way following the discovery of new aspects of themselves that they were previously unaware of. Further, the findings of this study also correspond with those of Heidegger in his presented view of 'finite autonomy,' as one may develop the ability to see more possibilities in front of them due to an increased sense of openness (Schürmann & Critchley, 2008). Participants in this study highlighted that living with terminal cancer enabled them to be more open to aspects of themselves which they were previously closed to and facilitated self-development.

6.5. Finding Comfort through Connection

A fourth group experiential theme identified in this study was *Finding Comfort Through Connection*. The sub-themes include connecting with self, forging a connection with God or a higher power and feeling connected to nature.

A significant finding reported in this study is the importance of connection with self, God or higher power and nature for patients while living with terminal cancer. The findings of this study contribute to our understanding of the wide range and diverse ways in which spirituality may be expressed at end of life by terminal cancer patients. The expression of spirituality goes beyond connecting with God or a higher power and also includes the connections forged with themselves and the world around them. Participants in this study highlighted that the experience of cancer provided them with the opportunity to regain a sense of connection with themselves despite living with a terminal illness. Connecting more deeply with self-enabled participants to find a sense of emotional balance, self-acceptance and self-compassion. Previous research has suggested that people may be considered as beings in relationship with self and others, and when illness occurs for a person, it impacts all of the aspects of their relationships, such as the relationship between mind and body, with family and other connections and their relationship with the transcendent or God (Sulmasy, 2002; Rego & Nunes, 2019). Sulmasy (2006, p.17) posited that "illness is a spiritual event," which causes a disturbance in both body and soul and which triggers spiritual questioning in matters such as existence, connection, meaning and value at end of life. Participants in this study highlighted that, while initially they felt that they lost their connection between mind and body due to their terminal illness, the experience of terminal cancer also provided them with opportunities to connect on a deeper level with themselves. While undergoing treatment, participants focused upon their own psychological and physical health which they often had not consciously thought about previously. Further, they used this period as a time to engage in reflection and became more self-aware than they had been previously. Several participants engaged in alternative therapies and counselling sessions as a means of finding balance. Through engaging in these spiritual practices, participants connected their mind, body and spirit in a meaningful manner to find balance, self-awareness and self-acceptance.

The findings of this study support previous research on the importance of psychological and spiritual wellbeing for patients living with terminal cancer. The spiritual dimension of being human encompasses connectedness, meaning, purpose, hope and transcendence (Harrington, 2016). Existing literature highlights that self-awareness is an essential component of psycho-spiritual wellbeing for patients with advanced cancer (Lin & Bauer-Lu, 2003). As patients become more self-aware and balanced, they become more self-compassionate. Self-compassion allows individuals to gain a more healthy attitude towards themselves through being kind to one’s self, being mindful and taking a balanced view towards a given experience and gaining understanding that one’s experiences are part of the common experience of humans (Neff, 2003; Neff & Vonk, 2009; Allen & Leary, 2010). Self-compassion may be a source of resilience and strength when faced with difficult and strenuous situations in life (Bluth & Neff, 2018). More specifically, a systematic review conducted by Mesquita Garcia and colleagues (2021) examining self-compassion in hospice and palliative settings suggests that self-compassion was associated with increased psychosocial and spiritual wellbeing due to lower levels of stress, anxiety and loneliness for patients. The findings of this study support these previous findings and extend our knowledge in this area by highlighting the ways in which individuals living with terminal cancer experienced wellbeing and emotional balance through gaining a connection with their sense of self and being compassionate towards themselves.

The current study highlights how religion and spirituality played a significant role for patients in living with a terminal cancer diagnosis. This finding mirrors previous literature documenting the importance of both religion and spirituality in the terminal cancer experience (Alcorn et al., 2010; Epstein-Peterson et al., 2015; Steinhauser et al., 2000). Connecting with self regularly through reflection and spending time connecting mind and body provided participants with a sense of wellbeing, relief from psychological and spiritual distress and to live in a meaningful way. This finding is consistent with previous literature which highlights how receiving a life-limiting diagnosis can trigger an increased awareness of, and engagement with, religion and spirituality as patients reflect on their vulnerability, priorities and meaning in life and where this awareness may influence increased spiritual practice and spiritual growth (Baldacchino et al., 2012). This awareness of religion and spirituality and the prioritising of time for inward reflection has also been referred to in previous literature as the beginning of a spiritual journey for patients who are faced with their mortality (Harrington, 2004). Kuhl (2011) posited that a spiritual journey is a process of inner reflection of one's values, meaning and purpose in life and where, during terminal illness, one can transcend beyond suffering and despair to find a deep connection with self, a higher power, and the world around them. This spiritual journey may be considered as a dynamic process of self-discovery where an individual learns more about themselves and reflects on who they want to be in the world and where one has an opportunity to find meaning in their illness and purpose in life (Richardson, 2014). The findings of this study reflect those within existing literature suggesting that spirituality enables individuals to gain a deeper connection with self and may enable those living with terminal cancer to learn about themselves.

A further finding of the current study in relation to connection is that as people living with terminal cancer connected with God or a higher power and engaged with religious and spiritual practice, such as prayer or meditation, they experienced greater levels of comfort and meaning. Religion and spirituality helped alleviate psychological distress and despair in participants in this study. Further, spiritual and religious beliefs and practices have been found to help terminal patients to cope (Alcorn et al., 2010), to find comfort and strength (Delgado-Guay et al., 2013) and to find peace (Balboni & Balboni, 2018) as they approach end of life. Spirituality and religion have been identified by participants in the current study as having a positive influence on participants' coping and wellbeing. This finding builds on research from Puchalski and colleagues (2014) who found that spirituality and religion helped patients to change their perspective of life while living with terminal cancer and to find new meaning. This study’s findings also mirror Ellis and colleagues' (2015) study which suggested that spirituality helped patients to transform how they viewed themselves and the world, to live with their suffering and to develop a new sense of meaning as they lived in the palliative phase of advanced cancer. The findings of a systematic review conducted by Moreno & Stanton, (2013, p.421) suggested that advanced cancer patients experienced personal growth, which they defined as “the perception of positive changes,” through enhanced relationships with others and connections, increased life appreciation, heightened spirituality and increased meaning-making as they engaged in life reflection at end of life. The findings of this study reflect former studies endorsing the importance of connection with God and higher power through spiritual practices at end of life.

Participants in this study also reported that connecting with nature provided them with a greater sense of wellbeing and peace. Participants highlighted that they found peace in the outdoors as they felt that they played an active part within the world around them when they were connected with nature. Peoples and colleagues (2018) highlighted that spending time in nature allowed people to gain a greater sense of meaning in life as they understood that there was ‘something bigger’ than oneself and their illness through gaining perspective on the transience of life. The findings of this study suggest that spending time in nature allows terminal cancer patients to gain a greater sense of connection with the world around them enabling them to release suppressed emotion and find peace, increasing their overall quality of life.

6.6. Navigating the Social World

A fifth group experiential theme identified in this study was *Navigating the Social World*. The sub-themes include feeling detached from others, relating to other terminal cancer patients and cultivating meaningful relationships.

Participants in this study highlighted that they felt disconnected from others, including some family members and friends, following their diagnosis with terminal cancer. Despite having previously maintained a close relationship with these people, participants reported that they experienced both physical and emotional distancing from others which led to them feeling isolated. Murray and colleagues (2007) also found that, in the terminal phase of cancer, one's social world becomes reduced from being wide to very narrow consisting of just family and themselves, as other people such as close friends feared cancer and the ultimate destination facing patients with a terminal diagnosis. Further, this finding relating to detachment from others echoes previous studies which suggested that individuals distance themselves from those living with terminal illness due to fears surrounding their own mortality and their desire not to be reminded of their own vulnerability to death, causing a disconnection between terminal cancer patients and those around them (Smith & Kasser, 2014). This fear of one's own mortality and one's decision to distance oneself from those living with terminal cancer may be explained by terror management theory. Terror management theory was developed from the works of Becker (1963; 1973) and posits that humans adopt a dual-defence approach (including distal and proximal defences) to protect themselves against mortality salience (Greenberg et al., 1986; Pyszczynski et al., 1999). This theory proposes that human motives (that shape human behaviour) are based upon one’s biological inclination for self-preservation (Solomon et al., 1991).

While terror management theory has been investigated in the context of how terminally ill patients cope with their illness (Maxfield et al., 2013; Svet et al., 2023), and more recently, in the context of terminal cancer patients specifically (Willis et al., 2023), the findings of this study suggest that terror management theory may also be useful for explaining the behaviour of those surrounding terminal cancer patients at the end of life, as the perceptions of participants in this study suggest that those around them retreat from them due to the difficulty they have with coming to terms with the finitude of existence. These findings are supported by those of Smith and Kasser (2014) who found that participants in their study would distance themselves more from someone with terminal cancer than someone with arthritis due to the mortality salience that they feel. The findings of this study suggest that from the perspective of terminal cancer patients, friends and family surrounding them may actively distance themselves in an act of self-preservation; however it must be acknowledged that, while this behaviour protects themselves, it may result in negative outcomes for the patient themselves.

In light of the perceived physical and emotional distancing of others, participants in this study highlighted that they experienced negative feelings such as isolation and loneliness at end of life due to their terminal condition. Participants felt that others did not understand their situation as nobody surrounding them had or was currently living with terminal cancer too. These findings correspond with the Heideggerian view that death is one’s own-most, is non-relational and not to be outstripped and therefore, has to be faced alone and cannot be shared

(Heidegger, 1927). Traditionally, research has suggested that patients who are dying experience a sense of loneliness as their pain is often intensified when they are struggling to cope with their respective illness and existential concerns (Dubrey & Terrill, 1976; Rokach, 2000; Rokach, 2003; Heidary et al., 2023). Specifically, research has shown that patients with a lack of acquaintances or visitors and a lack of familial support are liable to experience higher levels of loneliness and isolation than others with an existing social support system around them (Ciraci et al., 2016). The findings of the current study support this view and draw attention to the detrimental impact that loneliness may have on terminally ill cancer patients' wellbeing at end of life due to the isolation and lack of understanding that they feel.

Participants in this study highlighted that creating and maintaining a connection with other terminal cancer patients was important to them while living with their disease. Through gaining connections with other terminal cancer patients, participants felt a sense of understanding and camaraderie among the group which was incomparable to the connections they had with others. While existing literature has examined the impact of peer support groups in those living with cancer (Dunn et al., 2003; Hoey et al., 2008; Hu et al., 2019) and caregiver contexts (Friedman et al., 2018; Carter et al., 2020), few studies have reported the impact of peer support in those living with terminal illness specifically. Ussher and colleagues (2006) highlighted that cancer support groups provide unique social support to patients due to the unique environment and sense of community created by members, where they can educate each other and experience unconditional acceptance. The findings of this study contribute to psycho-oncology literature as while they reflect findings from existing literature regarding the usefulness of peer-support in other illness contexts, these results focus on social support at end of life specifically, and they highlight that support groups may be beneficial for those living with terminal cancer and enhance their quality of life due to decreased feelings of distress and isolation.

A further finding of this study is that participants living with terminal cancer actively cultivated meaningful connections with those around them who they perceived to matter most. Participants in this study reported having a smaller number of connections in their lives but that each of these connections were more meaningful than the connections and relationships that they had fostered with others before their terminal diagnosis. Existing literature in the area of palliative care highlights the central part that meaningful relationships play at end of life for patients living with a terminal illness (Jacobsen et al., 2021). Studies have shown that improving and maintaining a meaningful relationship with loved ones is one of the main concerns of patients with terminal illness (Laakkonen et al., 2004; Miccinesi et al., 2012). The findings of this study reflect former findings in this area, specifically in the context of terminal cancer as participants highlighted that meaningful connections gave them a sense of meaning and purpose, which increased their levels of wellbeing. However, these findings further highlight the importance of meaningful connections as participants actively built and maintained meaningful relationships with others, rather than playing a passive role in being open to different relationships.

The findings of the current study in relation to navigating the social world also highlight the importance of familial presence and support in the lives of participants. Participants reported that regaining connections with others and strengthening existing relationships that they had was one of their most important activities at this point in their lives. Former studies focusing upon patients’ perspectives at end of life highlight that strengthening relationships with family members is a key concern of patients (Singer et al., 1999; Heyland et al., 2006). Taylor (2014) suggested that the experience of terminal cancer may result in patients experiencing a disconnect from their intimate relationships but that some may experience a reconnect to these individuals in a different way to the way that had before as they valued the time they had together more. The findings of this study further our understanding in the area of relationships at end of life as the participants in this study actively strengthened the relationships that meant most to them and removed themselves from meaningless or harmful relationships with others. These findings suggest that the experience of terminal cancer highlighted the importance of cultivating meaningful connections with others within the lives of terminal cancer patients and this encouraged them to craft their social relations in a more meaningful way.

6.7. Journeying with Hope

The final theme group experiential theme identified in this study was *Journeying with Hope*. The sub-themes include losing hope, finding hope and living with hope.

The findings of the current study in relation to hope suggest that, sometimes, the physical and emotional challenges associated with living with terminal cancer may cause individuals to lose hope at the end of life. Participants in this study highlighted that they felt that the incurable nature of their disease caused them to become hopeless for the future. The findings of this study also identified that hopelessness was experienced by participants immediately following a terminal diagnosis and during times of challenge, such as physical pain and treatment symptoms. One participant used the metaphor of “throwing in the towel” to depict how hopeless she felt for her future due to the physical challenges following treatment. Another participant used the allusion of “the Sword of Damocles” hanging over her head to describe how she lived with the knowledge that her health could suddenly worsen at any time, and therefore lived without hope in the possibility of a future.

While hopelessness was initially considered to be an aspect of depression, previous literature has recognised hopelessness as a distinct construct (Breitbart et al., 2000). Sullivan (2003, p.400) posited further that hopelessness may not be a lack of hope, but rather the loss of an attachment to a type of hope that a patient once possessed and noted that “if we are tied to a hope for survival that is sinking into the deep blue sea, we will be unable to see the other forms of hope floating before us.” The findings of this study mirror previous studies which identified the high incidence of hopelessness among terminal patients in the initial period immediately following diagnosis (Sachs et al., 2013). Participants in the current study also expressed feeling overcome with pain and experiencing suicidal ideation due to the trauma that they were experiencing. This trauma was intensified due to their feeling of hopelessness, which led them to feel ready for their lives to end at times. These findings and the metaphors and allusions used by participants provide further insight into hopelessness during the terminal cancer experience and build upon previous studies which have identified that hopelessness among terminal cancer patients is associated with symptom distress and uncontrolled pain (Sachs et al., 2013; Wang & Lin, 2016), resulting in a desire for hastened death and suicidal ideation (Chochinov et al., 1998; Breitbart et al., 2000; Rosenfeld et al., 2014; Heisel & Flett, 2022).

Participants highlighted that their journey with hope was a dynamic experience whereby they lost hope at times but at other times tried to live their lives with a different type of hope. The phrase ‘journeying with hope’ refers to the idea of moving forward in life with a positive outlook and sense of optimism. It suggests that participants live with the belief that their current difficulties will improve and that they can live with the positive expectation of achieving their future goals or reaching certain milestones. For participants in this study, this hope did not necessarily relate to their survival but often manifested as hope that one may have a better quality of life or for their pain to be managed. Participants highlighted diverse ways in which they could find a new sense of hope within their lives. According to Feldman and colleagues (2008), within the diversity of hope exists the potential of a redirection of hope. This concept of a re-direction of hope may be applicable to the terminal cancer experience as while participants of this study experienced hopelessness following their initial diagnosis and at certain periods while living with terminal cancer, participants also re-directed their hope towards living for as long as possible and for maintaining their quality of life. The re-direction of hope assisted participants of this study to live with less worry and to move forward with living life. The findings of this study also support those reported by Broadhurst and Harrington (2016). In their review, they identified a transition among terminal patients from a state from initial hopelessness and grief to having increased hope as patients adapted to living with dying and moved from hopes for a cure to hopes for peace at end of life. Similarly, Kuhl (2011) suggested that the transitional nature of living with terminal illness, where patients’ initial hopelessness and depression moved towards hope and peace. The findings of this study reflect these former studies, suggesting that living with hope offered participants the opportunity to look towards the future with positive expectation, despite the knowledge of their prognosis.

The findings of this study highlight the central role that hope played in participants' lives as they lived with terminal cancer. Participants used metaphors to provide further insight into what hope meant to them as lived with terminal cancer. For example, one participant used the metaphor of planting flowers in the garden and having hope that they would grow. By using this metaphor, this participant suggested that hope was something that needed attention and needed to be nurtured in order to grow and thrive. A further metaphor used by some participants was that hope was a candle or a light that would shine through times of darkness and despair to light the way forward and to brighten the darkness when dealing with difficult emotions. These findings are particularly insightful in helping us to understand what it means for patients to live with hope during the terminal cancer experience. These findings provide additional understanding of what hope means to individuals and how hope helps individuals to live with terminal cancer. They contribute and build upon recent literature which identified the role of hope as being an integral aspect of the experience of living with terminal cancer (Baczewska et al., 2019; Broadhurst & Harrington, 2016). The findings of this study further identified that hope was both personal and subjective in nature, and the meaning of living with hope during terminal illness differed for each participant.

In this study, there were diverse ways in which hope was perceived among participants. Participants highlighted different aspects of hope that were most important to them. For some, hope was as an abstract belief. For others, it was an appreciation of future possibilities that could come to pass, while being cognisant of limitations. In these cases, hope was a motivating factor in life and was equated to optimism and looking towards the future with less worry, while being realistic of the prognosis. For other participants, hope involved setting small personal goals for the future, or creating milestones to aim for and achieve and to move forward with life. For these participants, it was a way of strategizing specific goals or milestones, such as birthdays or Christmas. These findings are important as they indicate different dimensions of hope for patients living with terminal cancer. The findings increase our knowledge and understanding about hope in terminal cancer and build upon previous studies which highlighted the subjective nature of hope (Broadhurst & Harrington, 2016; Nierop-van Baalen et al., 2016) and how living with hope contributed to meaning making during the terminal cancer experience (Möllerberg et al., 2019). The findings of this study identified that hope was individually constructed by each participant and acted as a strategic resource that participants in this study used to live well with terminal cancer. This finding builds upon previous literature such as Nierop-van Baalen and colleagues (2016) who identified hope as a thought construct which was subjectively created by individuals to create future oriented goals. Participants in this study created personal goals and milestones to help them to navigate through their times of struggle and adversity and to survive to see better days ahead. By engaging in strategies to move forward, participants created hope and positive expectation for themselves and lived with optimism for the future. These findings build upon previous studies as they identified that self-created hope was a strategy which aids terminal cancer patients to live positively, and which optimises the possibility of them remaining alive for longer and having increased quality of life. The findings of this study also build upon and provide new insight into the experience of hope, as they suggest that there are multiple dimensions of hope in the terminal cancer experience. Further, the findings indicate that hope is individually constructed and acts as a strategic resource to live well while living with terminal cancer.

The findings of this study suggest that maintaining hope helped to alleviate participants' feelings of despair and worry about their situation and helped them to live each day and look towards the future with positive expectation. These findings reflect previous literature such as Aase Schaufel and colleagues' (2011) who identified the positive role of hope in helping patients to cope with facing their own mortality and to alleviate existential distress when living with life threatening disease. This finding provides additional insight into how living with hope helps patients to alleviate physical, emotional and spiritual distress and increases their wellbeing and quality of life. This finding mirrors previous literature which identified hope as being an essential resource in improving quality of life and psychological and spiritual well-being (Sachs et al., 2013) as well as reducing pain (Nierop-van Baalen et al., 2016) for patients living with terminal cancer. While participants of this study believed that having a hopeful outlook towards life was integral to their wellbeing while living with terminal cancer, they experienced continual periods where they fluctuated between states of hopefulness and hopelessness. This finding adds to previous research, which identified both hope and hopelessness as separate and often co-occurring constructs, each of which has been found to impact the quality of life for terminal cancer patients.

The findings of this study highlight how for some participants, hope consisted of participants creating small meaningful and personal goals to attain at a future timepoint. This creation of goals and possessing the inner resolve to successfully achieve these goals is consistent with Snyder’s hope theory. According to Snyder, hope is defined as “the process of thinking about one’s goals, along with the motivation to move toward (agency) and the ways to achieve (pathways) those goals” (Snyder, 1995, p.355). In this model, hope comprises both cognitive and affective aspects and consists of a dynamic process of having goals, ‘agency thinking,’ and ‘pathways thinking’ (Snyder, 2002). Agency thinking involves “thoughts that people have regarding their ability to begin and continue movement on selected pathways toward those goals” (Corn et al., 2020, p.452). This type of thinking provides the motivation for the pursuit of goals. Pathways thinking involves creating or envisioning strategies and pathways to achieve these goals (Snyder, 2002; Snyder, 1994). This theory also emphasises how hope is an important source of resilience for individuals as they pursue their goals and is an important determinant in the attainment of positive outcomes (Gallagher & Lopez, 2017). Hope is an integral resource for terminal cancer patients to live with meaning in life and to cope during times of challenge and adversity (McClement & Chochinov, 2008; Tugade et al., 2014). While Snyder’s hope theory may be useful in explaining hope in terms of goal setting for some participants, the findings of this study highlight that there are other dimensions to hope, apart from personal agency and motivation. The findings of this study indicated that hope may also be an abstract belief or an appreciation of future possibilities that may come to pass, while being cognisant of limitations. These findings suggest that Snyder’s theory may be extended to incorporate these dimensions of hope in the terminal cancer experience.

The findings of this study highlight the dynamic nature of hope, and how individuals can oscillate between states of hopelessness and hopefulness. However, despite these fluctuations in emotional states, the strength of participants’ belief in the power of hope helped them to look towards the future with optimism, despite the uncertainty of the future. It is also noteworthy that while participants lived with hope for the future, they were also realistic in their expectations and adapted their hopes as they lived with the reality of their illness. These findings build upon previous literature, such as Daneault and colleagues (2016) who found hope to be a dynamic phenomenon. Their findings suggested that, as illness advanced, terminal patients' hopes for their future changed, with hopes for a cure shifting to prolonged survival and then shifted further to hopes for improved quality of life. Similarly, Low and colleagues (2007, p.215) described a wide "spectrum of hope" whereby patients adapted their hopes according to their current situation, such as over time replacing hopes for a miracle cure to hopes for finding meaning or having a peaceful death. Further, the findings of this study identify how for participants who believed they were nearing end of life, hope was viewed as the one thing they could "cling to." Phrases such as "hope never abandons you, you abandon it" and "where there's life, there's hope" provide additional insight into how important hope was for participants during terminal cancer and even up until the end of life phase of the disease. This study adds to existing research which found that terminal cancer patients continue to live with hope during the final months and weeks of life, and this hope evolves over time in new directions as patients move closer towards death (Breitbart et al., 2000; Feldman et al., 2008; Sullivan, 2003). The findings of this study advance literature as they suggest that patients may oscillate between hopelessness and hopefulness at end of life rather than experience a distinct transition or shift in a unilateral direction from hopelessness to hopefulness. The experience of terminal cancer patients was highlighted as being dynamic in terms of hope as one travelled across the spectrum of hope along their terminal cancer journey.

6.8. Evaluating the Research

A diverse range of approaches have been developed to assess the validity and reliability of qualitative research by various authors (Elliott et al., 1999; Tong et al., 2012; Yardley, 2000). The approach which was developed by Yardley (2000) was used by the researcher of this study to assess its validity and reliability due to its widespread use across qualitative studies in health psychology (Yardley, 2000) and its applicability and relevance to IPA (Shinebourne, 2011). Yardley (2000) suggested four principles to assess validity and quality of qualitative research. These principles include 'sensitivity to context,' 'commitment and rigour,' 'transparency and coherence' and 'impact and importance.' This study will be assessed on the basis of each of these four principles.

Yardley's first principle to assess the quality and validity of qualitative research is sensitivity to context. According to Yardley (2000), it is important that the researcher demonstrates a familiarity with relevant literature on the research topic and an awareness of the philosophical underpinnings of the qualitative approach being adopted. In addition, the researcher must demonstrate a sensitivity to the socio-cultural context and to the participants partaking in the study (Yardley, 2000). At the beginning of the research process, the researcher conducted an extensive qualitative review and meta-synthesis of recent literature to gain a familiarity with the research topic, to establish a research question and to provide a rationale for the aim of the current study. This review was set out in chapter two of this thesis. The methodology chapter demonstrated an awareness of the philosophical underpinnings of IPA, namely phenomenology, hermeneutics and ideography and a knowledge of IPA as a methodology. In the empirical methods and results chapters, the researcher demonstrated a sensitivity to the socio-cultural context and participants of the study. This is evident from the researcher's choice of IPA as a method in investigating the lived experience of a significant life event, such as living with terminal cancer and what it means to each participant, in the context of their life. The researcher also demonstrated sensitivity throughout the recruitment and data collection phase through the adoption of an online recruitment strategy and the development of a protocol for interviewing vulnerable participants online during the Covid 19 pandemic. A sensitivity to participants was demonstrated throughout the analytic process also, through careful and detailed analysis of the data and the extensive use of verbatim quotes to support the personal experiential themes (PETs) being outlined and to give voice to each participant.

Yardley's second principle is commitment and rigour. According to Yardley (2000), commitment refers to a researcher's prolonged engagement with the research topic and the researcher's immersion in the research data. In this study, the researcher demonstrated commitment and perseverance to the research through adapting the recruitment and data collection strategies during the Covid 19 pandemic restrictions. The researcher also demonstrated commitment to vulnerable participants by engaging with them with respect and sensitivity to their needs, such as planning interviews around treatment schedules and postponing interviews in some cases due to participant symptoms. Rigour refers to "the thoroughness and completeness of the data collection and analysis" (Yardley, 2000, p.221). The researcher displayed rigour throughout the data collection and analysis phases of the research. The empirical methods chapter provides a detailed explanation of the data collection process and the steps undertaken by the researcher in conducting the analysis. The analysis of the data was conducted on a case by case basis, and its focus was on idiography and on the convergences and divergences across cases. The experiential data supporting the researcher's analysis are presented in Appendix J. Additionally, the sample size in this study, it is greater in size than other published studies that have used IPA (eg. McTiernan & O'Connell, 2014; McGhee et al., 2022; Rodriguez-Prat et al., 2022) and is commensurate with the ideal number of participants as cited by the seminal authors in their publication and from personal communication with two of the seminal authors in the IPA method (Smith et al., 2021; Smith & Nizza, 2022). Additionally, it is also important to highlight that this research aimed to provide rich and evocative accounts of the experience of living with terminal cancer given the highly idiosyncratic nature of this experience and therefore, generalisability was not the intent of this study.

According to Yardley's (2000) third principle, transparency and coherence must be evident in the research process. Transparency refers to "the degree to which all relevant aspects of the research process are disclosed" (Yardley, 2000, p.222). Transparency was demonstrated by the researcher by the clear and detailed description of each aspect of the data collection and analysis processes, including participant recruitment, interview schedule and interview protocol and outlining each of the stage of the analysis. Additionally, the researcher engaged in continuous reflexivity throughout the research process. A detailed account of reflexivity was outlined by the researcher in the methodology chapter. Coherence refers to how clearly a research question may 'fit' with the philosophical approach used, and with the method of investigation and analysis conducted (Yardley, 2000). The aim of this study was to investigate the experience of living with terminal cancer. IPA was deemed the most appropriate method of investigating this phenomenon. IPA is a qualitative method which is concerned with the investigation of a significant personal lived experience, the meaning of that experience to individuals in the context of their lives and how they make sense of that experience (Smith et al., 2022).

Yardley's fourth principle is impact and importance. According to Yardley (2000, p.223), impact and utility are "the decisive criterion by which any piece of research must be judged." For a piece of research to have impact, it should help to provide a new understanding of a topic and in the case of health research, it may contribute to and inform healthcare practice (Yardley, 2000). The findings of this current study provide new understanding in the experience of living with terminal cancer. It furthers our knowledge about how patients initially experience a loss of control following a terminal cancer diagnosis, however, it provides insight into how, by educating oneself and engaging in self-management, patients can regain control and learn to live with the uncertainty of their future. The findings of this study provide a deeper insight into the experience of participants' perception of time and how they prioritise time in their lives. The findings offer further knowledge about how patients adapt to changes in identity and re-define their identity. The findings also provide an insight into the importance of connecting to oneself, God or a higher power and nature for terminal cancer patients. The findings provide a deeper understanding of the role of relationships with family, friends and other terminal cancer patients and how these can impact the wellbeing of patients. Finally, the findings provide insight into hope, what it means for patients and how having a belief in hope can help patients to look positively towards the future, despite their shortened life expectancy. These findings advance our knowledge about the experience of living with terminal cancer and may also inform future healthcare policy and practice in the provision of compassionate care for terminal cancer patients.

6.9. Limitations of the Empirical Study

A limitation of this study is that all participants included in this study were all living well as they had lived beyond their poor prognosis, apart from one participant who had not yet lived past her prognosis. Hence, while this study provides a unique insight into how terminal cancer patients live their lives, the findings of this study may or may not be applicable to patients living with terminal cancer or those who are living with advanced cancer or other terminal illnesses such as motor neuron disease. A further limitation of the study is that it was not possible for the researcher to use a PPI approach to incorporate patients' views in the analysis as it would have been inconsistent with the IPA methodology which involves the use of a double hermeneutic in the interpretation of thematic content.

6.10. Conclusion

In conclusion, this discussion chapter has highlighted and discussed the key findings stemming from this empirical study within the context of existing literature in this area. The results stemming from each group experiential theme identified in chapter five were discussed and contextualised within the relevant body of literature that this finding stemmed from. Further, the contribution that each of these themes and results had was outlined to further our understanding of the phenomenon of living with terminal cancer, in line with the aims of the study. Additionally, a thorough evaluation of this research was conducted to demonstrate the validity and reliability of this empirical qualitative research study, in line with best practice. Finally, the limitations associated with this empirical study have been acknowledged. The original theoretical contributions to literature as well as the practical contributions to healthcare practice and policy that this study makes will be further developed in the next chapter.

Chapter Seven:
Conclusion

“Hope is being able to see that there is light despite all of the darkness”

Desmond Tutu.

Chapter Seven

Conclusion

7.1. Introduction

This chapter will review the key findings from both the meta-synthesis and the empirical study conducted as a part of this doctoral thesis and the original contribution of this research will be outlined. Following this, the contribution of this research to existing literature, to clinical practice and to policy development will also be highlighted. Additionally, the limitations of this research will be acknowledged and future directions for research in this area will be suggested. This will be followed by a concluding statement.

7.2. Overview of Key Study Findings

7.2.1. Key findings from qualitative meta-synthesis

The qualitative meta-synthesis explored and synthesised the literature that was available between March 2009 and March 2022, to offer an insight into how those living with terminal cancer experience spirituality. To the researcher's knowledge, this was the first meta-synthesis that focuses particularly on spirituality in patients living with terminal cancer. To overcome the uncertainty surrounding the distinction between advanced cancer and terminal cancer that exists within oncology literature and to provide a foundation for the meta-synthesis that was undertaken, an operational definition of terminal cancer has been provided. Terminal cancer was operationally defined as cancer that is advanced with a prognosis of less than one year. Through the exploration, consolidation and synthesis of definitions from existing studies, the operational definition and the distinction between terminal cancer and advanced cancer highlighted in this study is significant as those who are terminally ill maintain the awareness that their death is imminent. The provision of this definition provides clarity for future research in this field as it will enable researchers to distinguish between those living with different types of advanced cancer avoiding ambiguity within research populations included in studies in this field of research and will encourage researchers to focus on the hidden population of terminal cancer patients specifically.

The findings of the meta-synthesis suggest that spirituality can positively impact the lives of terminal cancer patients. While it is acknowledged that, to a certain extent, these findings illustrate the challenges faced by individuals who are spiritually distressed, these results also highlight the beneficial impact that spirituality may have on a person's sense of identity, meaning, and purpose in life as they live with terminal cancer. While previous research indicates that religion or spirituality may not always have a positive effect on individuals with terminal cancer (King, 2012), this review identifies spirituality as a means through which an individual may navigate through the uncertainty of their terminal cancer journey and it highlights how transcendence from suffering may occur through transformation of self. This meta-synthesis makes an original contribution to literature as it goes beyond identifying the state of evidence in this field and provides new insights into the experience of spirituality, as this is the first meta-synthesis exploring spirituality from the perspective of terminal cancer patients specifically. Through exploring and synthesising the literature, this qualitative meta-synthesis highlights that spirituality may facilitate one living with terminal cancer to experience peace at end of life and to live well while dying, despite the awareness of one’s terminal condition and impending death.

While earlier reviews in the field of spirituality have emphasised the value of addressing patients' spiritual care needs at the end of life (Clyne et al., 2019; Edwards et al., 2010), this meta-synthesis makes a unique contribution to the literature in the field by focusing on the most current studies on spirituality as it is experienced by terminal cancer patients. It also demonstrates the transformation that one may experience as a result of learning to cope with higher levels of hardship and distress, and learning to achieve inner peace in difficult circumstances. According to this meta-synthesis, spirituality may serve as a catalyst for experiencing this change from suffering to serenity. The results of this meta-synthesis also draw attention to the conflict between the anguish of meaninglessness and the potential for spiritual solace that may be discovered through personal growth in this context. These findings enhance our knowledge of the experience of living with terminal cancer as it shines a light on the dichotomy experienced by terminal cancer patients through gaining an insight into both the suffering and growth that one may experience as one approaches end of life. This meta-synthesis offers insight into the wide expression of what spirituality can be at end of life through connection to the world around them including aspects of one’s life such as connection to nature or others, rather than focusing exclusively on connection to God or a higher power. Notably, the findings of this qualitative meta-synthesis contribute to our understanding of living with terminal cancer as the comprehensive synthesis of research highlights how spirituality is useful and beneficial in this context.

The findings of this meta-synthesis can be used to inform future healthcare practice as they highlight the importance of the provision of spiritual interventions for those living with terminal cancer to help them live well. Further research in the area of spirituality and terminal cancer would be beneficial to researchers to provide a holistic understanding of the perceived spiritual needs and concerns of terminal cancer patients from several perspectives including but not limited to healthcare professionals and informal caregivers to provide insight into how spirituality is experienced in one's final days, which is not possible to explore from a patient's perspective. Further, more studies focusing on terminal cancer patients' perspectives are very important as they can provide deeper insight into their existential and spiritual needs as they live with the knowledge of their reduced life expectancy. Further research focusing on the perspectives of those who are living with terminal cancer would be particularly valuable as it has the potential to inform the type of compassionate end of life care and support that is needed to help individuals live while dying.

7.2.2. Key findings from empirical study

The empirical study conducted as part of this PhD thesis aimed to explore the phenomenon of living with terminal cancer from the perspective of terminal cancer patients themselves. This research is necessary to provide a better understanding of this phenomenon and to truly appreciate the complexity of this unique experience, in response to the call highlighted by Willig and Wirth (2018).

The findings of this research offer an original contribution to literature as they illuminate and evoke rich insights into the experience of living with terminal cancer in an in-depth manner, which previous research has not yet acknowledged in this context. The findings of the empirical study suggest that living with terminal cancer is both a complex and multidimensional experience where one's biological, psychological, social, spiritual and existential functioning is affected by their disease. While former studies examine the impact that advanced cancer has on one's physical (Choi et al., 2022) and psychosocial functioning (George et al., 2020; Chinh et al., 2020; Martin-Abreu et al., 2022), this empirical study provides further insight into how one's spiritual and existential wellbeing may be affected while living with terminal cancer through themes identified such as *'Recovering Control in Uncertain Times,'* '*Gaining an Increased Awareness of Time,' 'Negotiating a Changing Identity,' 'Finding Comfort through Connection,' 'Navigating the Social World'* and '*Journeying with Hope.'* The findings of this study shine a light on these unique facets of the experience of living with terminal cancer which were not well understood within existing literature and further highlight the multidimensional and complex nature of this experience. Participants within the empirical study reported that while they experienced spiritual and existential challenges due to their terminal illness, spirituality has helped them to overcome physical, psychosocial, spiritual and existential challenges that they faced when living with terminal cancer, building on the findings of the meta-synthesis. These findings have the potential to inform future healthcare policy and practice of the unique concerns of those living with terminal cancer due to the complex nature of this phenomenon and highlight the importance of considering spirituality at end of life for terminal cancer patients.

The research findings stemming from the empirical study enhance our understanding of the role of time as one lives with terminal cancer. Different metaphors referring to time such as the ‘loud ticking in the back of your head’ highlight the salience of time in the lives of those living with terminal cancer. While the findings of this study suggest that one’s awareness of one’s terminal disease can cause existential angst and spiritual distress, the findings of this study offer a unique insight into how one’s increased awareness of time can also have a positive impact on living with terminal cancer. The increased awareness of time and their finitude made participants aware of the time that they had left to live and its value to them and their families. This awareness of time enabled participants to move past suffering from existential angst and allowed them to focus on valuing the time they had left in their lives and living well despite their terminal disease. This sense of value and appreciation was often rooted within the experience of spirituality as they moved past existential and spiritual suffering to a position of appreciation and gratitude. While former research has suggested that spirituality may be effective in alleviating pain at end of life (Wachholtz et al., 2016), the findings of this study build on these former findings and maintain the view that spirituality played a central part within participants’ lives and significantly influenced their ability to cope and live with terminal cancer in a positive and meaningful way by transforming their perspective. Participants maintained diverse views of spirituality and these findings built upon those of the meta-synthesis highlighting the wide expression of spirituality as while some participants did not exclusively focus on religion or faith at end of life, they found peace and solace in the relationships they cultivated and the connections they had with the world around them. These insightful results may be used to adapt pre-existing spiritual interventions or to inform future interventions that can be used within the care plans of those living with terminal cancer focusing on reframing the concept of time and highlighting the importance of relationships and connections for those living with terminal disease.

Significantly, participants in this study highlighted that the experience of living with terminal cancer was transformative in several ways. While participants found themselves becoming a terminal cancer patient and experienced a sense of loss in terms of their own former identity, spirituality facilitated them in gaining a greater connection with self and enabled them to discover aspects of themselves that they were previously unaware of. While Ellis and colleagues (2015) highlighted that those with advanced cancer may experience a transformation through suffering and post traumatic growth following their diagnosis, the findings of this study build on existing knowledge and suggest that this transformation may be multidimensional in nature. This multidimensional transformation is demonstrated through the themes identified in this study such as *'Negotiating a Changing Identity'* where one shifts between past and present identities to re-define oneself, and *'Recovering Control in Uncertain Times'* as one spirals out of control and learns to live with uncertainty by regaining a sense of control. These findings contribute to our knowledge of the experience of terminal cancer as while previous literature highlights that the experience is dynamic, the findings of this study shine a new light on this phenomenon and highlight that living with terminal cancer can be a multidimensional and transformative experience in the lives of participants.

Importantly, the findings of this study provide a unique contribution to existing literature as they suggest that one may oscillate between the states of hopelessness and hopefulness as they live with terminal cancer. The findings of this study support the idea that living with terminal cancer can represent a journey with hope for participants due to the fact that the experience in itself is complex, dynamic and multidimensional in nature. While participants reported feeling hopeless at times due to the incurable nature of their disease, they also posited that hope played a central role in allowing them to live well. Participants highlighted that their experience with hope was dynamic whereby they had to find a new type of hope that did not necessarily relate to their survival but often manifested as hope that one could have a better quality of life or could effectively manage their symptoms. While former studies suggest that hope is a dynamic phenomenon (Daneault et al., 2016), this study provides a further insight into the experience of hope from the perspective of terminal cancer patients. Therefore, rather than experiencing a distinct transition or unilateral shift from hopelessness to hopefulness, these findings support the view that one may oscillate between states of hope as they live with terminal cancer. The findings of this study contribute to our knowledge focusing on the concept of hope as a dynamic concept that can mean different things to participants across the terminal cancer trajectory. According to the findings of this study, hope may be an abstract belief, it may be an appreciation held by participants of future possibilities that could come to pass or a way of strategising specific goals within the lives of participants as they look to the future with positivity.

7.3. Implications for Future Theory, Research, Practice and Policy Development

7.3.1. Implications for Theory and Research

Considering this thesis as a cohesive project exploring the phenomenon of living with terminal cancer, the findings produced in the studies making up this thesis offer a significant contribution to existing literature and have important implications for future research in this field.

To the researcher’s knowledge, the systematic review and qualitative meta-synthesis conducted as a part of this thesis (see chapter 2) is the first meta-synthesis examining spirituality in terminal cancer patients specifically. This study contributes to literature as it has identified, consolidated and comprehensively synthesised the findings of existing research that has examined the role of spirituality in the lives of those living with terminal cancer. While existing reviews had considered the spiritual care needs and spiritual perspectives of advanced cancer patients, this review is the first one to consider spirituality in terminal cancer patients specifically. Given the focus on spirituality as experienced by terminal cancer patients specifically, the four analytical themes identified in this meta-synthesis offer a unique and novel insight into the role of spirituality in the lives of those living with terminal cancer as they highlight the wide expression of what spirituality can mean to terminal cancer patients at end of life.

The findings of the empirical study offer novel insights into the experience of living with terminal cancer. Through exploring the experience of living with terminal cancer from the perspective of terminal cancer patients themselves, the findings of this study highlight the complexity and multidimensional nature of this phenomenon. These findings highlight that, while suffering and pain associated with existential angst and a lack of control over one’s life are experienced following one’s terminal diagnosis, the knowledge of one’s impending death can help them to live well. This study contributes to literature as, while participants may not have referred explicitly to spirituality during empirical data collection, they each described how they engaged in spiritual practices associated with each dimension of the experience of living with terminal cancer (such as spending time in nature associated with '*Finding Comfort through Connection'* and being hopeful for the future associated with '*Journeying with Hope'*) and these practices facilitated the transformation of their perspective and outlook on life. Based on these findings, spirituality has been highlighted as a facilitator in helping those living with terminal cancer to experience peace at end of life and to live well while dying. Future research should focus on exploring how spirituality may act a facilitator to finding peace in other contexts beyond terminal cancer such as the impact it may have in the lives of those living with other terminal illnesses.

A key contribution this study makes to theory is in the field of hope. The findings of this study highlight that hope is a dynamic journey across the trajectory of one's illness and that one may oscillate between states of hopelessness and hopefulness as one lives with terminal cancer. Building upon Snyder's theory of hope (1995; 2002), which highlighted that individual agency and goal-setting are key facets within the concept of hope, this study suggests that these goals may be adapted for those living with terminal cancer as they no longer wish for survival but to maintain a good quality of life. This adoption of hope was highlighted as a core facet of the terminal cancer experience as participants highlighted that being realistic about their prognosis enabled them to look towards the future with optimism, despite the uncertainty about the future and the limited possibilities available to them.

The results of this study suggest that hope is a diverse concept in the lives of terminal cancer patients and can mean many things to patients across the cancer trajectory. Based on the findings of this study, hope can be an abstract belief for participants, it can be an appreciation held by participants of future possibilities that could come to pass (while remaining cognisant of limitations) or a way of strategising specific goals or milestones within the lives of participants as they look to the future with positivity. These findings advance literature specific to the experience of hope at end of life for those living with terminal cancer. These findings suggest that existing theories of hope, such as Snyder's, need to be extended to cater for the diverse meanings of hope that may be held by participants in different contexts. In the context of terminal cancer, these findings suggest that hope is dynamic in nature and may change across the trajectory of the terminal cancer experience. These findings may also help to inform future research in new and novel areas such as Possibility Studies which focuses upon the processes and outcomes of engaging with the possible at a psychological and sociocultural level. Further, these findings may also or be used as a theoretical underpinning for examining hope in other contexts such as in other terminal illnesses beyond terminal cancer. Future research should explore the possibility of co-existence between different facets of hope such as 'feeling hopeless about finding a cure' but also 'feeling hopeful for tomorrow' in the context of illness.

7.3.2. Practical Implications

In addition to the significant contribution that this research makes to existing theory and literature, the findings of this study have the potential to make an important practical contribution to healthcare practice and the lives of stakeholders (including but not limited to patients, caregivers and medical professionals) affected by terminal cancer.

The findings of this study suggest that there is a requirement for further research into spiritual interventions within psycho-oncology to ensure adequate provision of whole person care for patients living with terminal cancer. Chochinov and Cann (2006) highlighted that spiritual interventions may enhance one's experience of dying by decreasing suffering and increasing their quality of life as they near death. Spiritual interventions may have different purposes such as focusing upon different aspects of one's being such as dignity therapy or meaning-making interventions in addition to alternative and holistic therapies used by patients (Kruizinga et al., 2016). The findings of this study relating to time highlight that these interventions may help patients to navigate through the existential and spiritual distress that they experience due to their knowledge of their imminent death. This recommendation for future research stemming from the findings of this PhD study echoes that of Steinhauser & Balboni (2017) who highlighted the importance of the development of spiritual interventions in palliative care settings to address the complex needs of terminally ill patients. Additionally, a Cochrane review conducted by Candy and colleagues (2012) suggests that spiritual interventions, when implemented correctly, may act as a buffer against a reduction in wellbeing and quality of life in terminally ill patients. Further findings relating to '*Gaining an Increased Awareness of Time'* and *'Navigating the Social World'* suggest that to alleviate their suffering, patients need the space and time to speak about their experience of living with life limiting disease and to give voice to how they make sense of this in their life. In this way, they can feel better supported, have their concerns understood and valued and live with better wellbeing and sense of dignity

(Ellis et al., 2015). The findings stemming from this research may be used to inform or develop the required spiritual interventions for cancer patients to minimise the suffering that they experience and maximise their wellbeing, enabling them to live well while dying.

The findings of this study focusing on '*Recovering Control in Uncertain Times'* may also have implications for self-management programmes and interventions for patients living with terminal cancer. The findings of this study suggest that the development of self-management strategies enabled participants to live well with their diseases and they could restore a sense of control within their lives, despite their terminal disease. The results stemming from this study focusing on both time and control have the potential to inform self-management programmes for patients living with terminal cancer as these findings shine a light on aspects of life that patients desire to control despite their terminal illness, such as adopting a healthy lifestyle, self-monitoring and meaning-making. Additionally, these findings support the view that educational interventions for patients living with terminal cancer may be beneficial for their quality of life as participants highlighted that educating themselves about their disease was a key factor in enabling them to restore a sense of control in their lives, to feel empowered and to advocate for themselves in coordinating their care and support as they lived with terminal cancer. These educational interventions can help patients beyond merely educating patients about their illness, but also educate them on how to live well with terminal cancer focusing on other findings from this research such as teaching them how to cultivate meaningful connections in their lives, focusing on reframing one's mindset and how to craft their identity in a meaningful way despite their terminal disease. The call for the provision of these self-management and educational programmes for patients suggest that those living with terminal cancer need to be considered within the cancer survivorship stream; rather than being classed as patients, these people desire to live well while dying, rather than being overlooked due to their short prognosis.

7.3.3. Implications for Policy Development

The findings of this study resonate with a call identified in the National Cancer Strategy 2017-2026 by the Department of Health, to gain a better understanding of not only the biological needs of cancer patients, but also their psychological, social and spiritual needs, in the Irish context. Further, this report acknowledged the importance of understanding and addressing the psychosocial and spiritual needs of patients across the cancer trajectory given the individual nature of the experience of cancer from different patient perspectives. This study provides a comprehensive understanding of the phenomenon of living with terminal cancer from the perspective of patients themselves. Within this study, the concerns of terminal cancer patients were considered and acknowledged as patients lived with the knowledge of their impending death. This is important to consider as these patients are a unique group that are often overlooked in the development of survivorship programmes due to their poor prognosis. The findings of this study can provide direction for future policy development in the area of psycho-oncology and cancer care as they highlight the importance of considering terminal cancer patients as a distinct group given the unique needs that this population have in comparison to other cancer patients. This group of patients require care beyond psychosocial support due to the increased existential and spiritual distress that they experience as they live with the knowledge of their terminal diagnosis and impending death. The findings of this study can aid policy makers in the development of the updated National Cancer Strategy post-2026 by providing them with a more nuanced understanding of the complexity of the terminal cancer experience, flagging the importance of highlighting the need for enhanced interventions focusing on meeting the physical, psychological, social and spiritual needs of terminal cancer patients specifically through the provision of patient centered care.

Further, the findings of this study relating to *'Gaining an Increased Awareness of Time'* and *'Recovering Control in Uncertain Times'* shine a light on the spiritual and existential concerns of terminal cancer patients and highlight the importance of continued investment in interdisciplinary support services to meet the complex needs of patients living with terminal cancer in Ireland. In addition to including the specific needs of terminal cancer patients in future policy documents such as the National Clinical Programme for Palliative Care, bodies such as the National Cancer Control Programme (NCCP) should devote resources to setting up supports specifically for terminal cancer patients such as peer-support groups given the positive impact that these may have on the lives of those living with terminal cancer. Additionally, based on these research findings, it is essential that additional resources are allocated by the Health Service Executive to ensure that interdisciplinary support from professionals in acute and palliative settings are provided to those living with terminal cancer and that psycho-oncology services are provided to those across the terminal cancer continuum from diagnosis to death, where required.

The findings of this study suggest the importance of psychosocial and spiritual support at end of life due to the complex and multidimensional nature of the experience of living with terminal cancer. The findings relating to time highlight that due to the highly idiosyncratic nature of this experience and the level of distress experienced by those living with terminal cancer, that individualised psychological support is necessary for those to cope with their distress and live well despite their terminal illness. Based on the findings of the qualitative meta-synthesis, spirituality has been identified as a facilitator or catalyst in enabling those living with terminal cancer from experiencing distress and suffering to gaining a sense of peace at end of life. Therefore, it is pivotal that future policy and psycho-oncology models of health highlight the importance of psycho-oncology, specifically focusing on psychosocial and spiritual care, within the care plans of those living with terminal cancer to meet their needs and allow them to live well while dying. For example, cancer nurses may be able to routinely ask terminal cancer patients about spiritual matters and existential issues within the lives of patients as a means of screening. Based on these screening questions, oncology nurses can provide those living with terminal cancer with follow-up information that links them with a peer-led support group to address these issues that are associated with the terminal cancer experience. These could be set up in collaboration with the cancer centres around the country or with support services such as Cancer Care West or ARC. The findings of this study can inform policymakers of the unique spiritual challenges facing terminal cancer patients so that they can influence policies to integrate spiritual care into care plans for patients to help alleviate spiritual distress and to develop spiritual interventions. The findings of this study may also influence policy development by highlighting the need to focus upon the importance of chaplains within the MDT who can provide training on existential issues and spiritual care needs to other members of MDTs and palliative care teams in hospital settings to truly meet the holistic needs of terminal cancer patients enabling them to live while dying.

7.4. Study Strengths and Limitations

This study has many strengths and contributes to literature in several ways. Firstly, the qualitative meta-synthesis conducted was the first meta-synthesis specifically examining spirituality in terminal cancer patients. This meta-synthesis produced novel findings in the area of terminal cancer and highlighted that spirituality can positively impact the lives of those living with terminal cancer as it may be a transformative experience that allowed individuals to move from suffering to solace at end of life. Further strengths of this study are that the qualitative method enabled the researcher to gain an in-depth insight into the experience of living with terminal cancer. This rich insight gained into the phenomenon of interest in this study was attributed to the depth of the qualitative data collected in this study which would not have been possible using a quantitative methodology. Each participant shared their story and experiences with the researcher in their own language using metaphors associated with their own narrative which enabled them to discuss their experiences in an unconstrained way, in which they were comfortable. A further strength of this study is that the voices of terminal cancer patients specifically are being acknowledged. Terminal cancer patients are often classified under the umbrella of advanced cancer patients and are therefore, often considered as a hidden population within research. As the experience of living with terminal cancer is unique and different to living with advanced cancer as one is aware of their impending death, gaining the perspectives of these patients is an evident strength of this study and contributes significantly to literature.

In line with the IPA principles which aim to include homogeneity in sampling (Smith et al., 2022), the sample recruited for this study was purposively homogenous in terms of participants' experiences of living with terminal cancer and the sociocultural context of where the study was conducted. Participants were all English-speaking adults who were resident in Ireland. Eight out of ten participants were of Irish heritage. Two participants were originally from the United Kingdom; one participant had lived in Ireland for thirteen years, while the other participant had moved to Ireland in excess of twenty years ago. Seven participants lived in urban areas close to large towns and cities, while three participants lived in more rural areas. All participants had access to cancer care services offered by the Health Service Executive in Ireland. While the majority of participants lived in relatively close proximity to hospitals, the three participants who lived in rural areas travelled extended distances to gain access to cancer care services. The provision of access to cancer care services for all participants may have led to the relatively positive outcomes among many of these participants.

Five participants reported that although they had previously been active members of the Catholic community in Ireland, they no longer engaged in religious practice, such as attending Church services. However, these participants continued to have religious and spiritual beliefs which influenced their outlook on life. Catholicism has been identified as a key aspect of the Irish cultural heritage and still has an impact on modern Irish society (Inglis, 2007). Additionally, five participants reported experiencing difficulties in communicating with healthcare professionals. Four participants perceived healthcare professionals as authority figures, who they perceived they could not question about issues regarding their health and their care. Some of these participants perceived that this reluctance to question medical staff was due to their beliefs and experiences of having a deference to authority, which they perceived was associated with their upbringing. In line with other European countries who follow Catholic tradition, in Ireland there has been a synergy between Catholicism and the paternalism inherent within the medical system (Toscani and Farsides, 2006). This paternalistic tradition may be responsible for the attitudes and beliefs of participants in terms of how they felt when communicating with healthcare professionals regarding decisions involving their own health and care. The homogeneity of this sample is considered as an inherent strength of this study as it provides an in-depth insight into the experience of living while dying within a specific cultural context (specifically within the Irish context).

While this study has many strengths, there are some limitations that must be acknowledged associated with this research study. Firstly, the meta-synthesis had a number of limiters that were specified during the literature searching and screening process which informed the inclusion criteria for the study. An example of a specific criterion is that only studies published in the English language were included in the review, and therefore, other studies published in different languages were not included in the review.

A further limitation of this study is that all patients were living with terminal cancer and were all living well as they had lived beyond their poor prognosis, apart from one participant who was doing well but had not yet lived past her prognosis. Hence, while this study provides a unique insight into how terminal cancer patients live their lives, the findings of this study may not be applicable to patients who are not doing well with terminal cancer, those who are living with advanced cancer or those with other terminal illnesses such as motor neuron disease. It also must be acknowledged that the data collection for this project took place during the COVID-19 pandemic in Ireland and hence, none of these patients were inpatients within a hospice setting and only some were receiving palliative care in an outpatient capacity. If patients were in a hospice or healthcare setting, they may not have had the sense of freedom that they were experiencing while receiving palliative care in an outpatient capacity and the experience may have been different to the way that this study suggests. Additionally, it is acknowledged that this study was conducted in Ireland, a developed country where patients had access to healthcare despite there being a global pandemic. This may not be the case in developing countries or for patients located in rural areas with no access to healthcare services.

7.5. Directions for Future Research

The findings of these studies have the potential to inform and set out clear directions for future research in the area of psycho-oncology and terminal cancer. Based on the findings identified in this study, it is suggested that future research should focus on terminal cancer patients and it is essential to provide a sense of clarity within literature by distinguishing between studies that focus on those with terminal cancer specifically and those with metastatic or advanced disease to highlight research focusing on this distinct group. As terminal cancer patients are a vulnerable population due to their awareness of their impending death, research should aim to build on the findings of this research and focus on gaining further insight into their experiences and preferences in terms of their care and also to understand how their wishes may change across their cancer journey. Additionally, future research in the field of oncology and cancer may benefit from highlighting if terminal cancer patients have specifically been included within their sample to differentiate between those living with advanced cancer and those who are deemed as terminal based on their prognosis.

A key finding highlighted by participants in this study was the increased awareness of time that they had following their terminal cancer diagnosis. The findings of this study suggest that this awareness had both positive and negative effects on the lives of those living with terminal cancer. While in this study, it seemed that the negative impact of this awareness of time immediately followed one's diagnosis and as one came to terms with this negative effect diminished, further research in this area would be beneficial in terms of examining this transition from despair to personal development. While the findings of this study suggest that spirituality may have acted as a catalyst in enabling one to make this transition, a further examination of one's awareness of time at end of life may be beneficial and could inform healthcare professionals of how one develops resilience at end of life and can experience growth or development through suffering.

Based on the findings of this study, further research examining identity from the perspective of terminal cancer patients would be beneficial. In this study, patients identified that there was a dichotomy that existed between their 'old self' and their 'new self' following their cancer diagnosis. Additionally, some patients identified that they struggled with the paradoxical nature of losing aspects of one's self to discover new aspects of themselves. Gaining further insight into the experience of terminal cancer and the impact this has on one's sense of identity and self would be beneficial in terms of informing healthcare professionals of how best to support terminal cancer patients and may inform self-management programmes focused on helping them to construct and craft their own identity despite their terminal disease.

Future research in the area of hope should aim to expand hope theory to accommodate the findings of this study. Longitudinal studies exploring one’s journey with hope may also provide valuable insights into the terminal cancer experience and the role that hope plays in their lives as they live with the knowledge of their poor prognosis. Nonetheless, it is acknowledged that it may be difficult to complete such research with terminal cancer patients due to the nature of their disease and their short prognosis. Further, longitudinal research could provide powerful insights into the perceived transformation through suffering that terminal cancer patients experience and explore what antecedents or factors may facilitate this transformation or what barriers may be minimising one’s potential to transform while living with terminal cancer.

Further research exploring the phenomenon of living with terminal cancer focusing on the perspectives of others may be beneficial and provide different insights into the experience than have been provided in this study. Research focusing on the perspectives of informal caregivers may provide insights into the experience that patients themselves may not have been willing or eager to share such as the level of their struggle to come to terms with their diagnosis or their emotional state when living in the liminal space with uncertainty. Further, through understanding the perspectives of informal caregivers, it is possible to gain rich insights into the experiences of terminal cancer patients at the very end of their disease as they immediately approach death, which is not possible to explore from their own perspective. Additionally, the perspective of medical professionals such as healthcare assistants, nurses and oncologists among others may be beneficial as they have experience in dealing with those living with terminal cancer and could provide insight into how patients’ needs change across the cancer trajectory and what factors may influence their quality of life when living with terminal cancer. In a similar way to caregivers, the perspective of healthcare professionals may offer insight into how participants live with terminal cancer as they move towards the end of life phase of their disease which is not possible to do from a patient's perspective. Through the exploration of this experience from multiple perspectives, the data collected may be triangulated to provide a holistic view of this complex phenomenon. Additionally, divergences within the perspectives of different groups can be identified and these findings can inform different stakeholders within the patient care team of how patients' experiences differ from theirs and educate them by showing them how to support the terminal cancer patient in line with their own wishes.

7.6. Concluding Statement

This thesis aimed to explore the phenomenon of living with terminal cancer. In the first study, the first qualitative meta-synthesis examining the experience of spirituality in terminal cancer patients was conducted. The findings of this meta-synthesis suggested that spirituality can positively impact the lives of those living with terminal cancer. It was highlighted that spirituality may act as a catalyst for experiencing a transformation from suffering to serenity as one lives with terminal cancer. This study offers novel insights into the experience of living with terminal cancer as it suggests that spirituality may significantly impact one's experiences and help one cope with their terminal disease, enhancing one's quality of life and ability to live well while dying.

The second study focused upon empirically exploring the experience of living with terminal cancer from the perspective of terminal cancer patients themselves. The empirical findings offer a number of original contributions to literature as they illuminate and evoke rich insights into the experience of living with terminal cancer in an in-depth manner. The empirical findings highlight that the experience of living with terminal cancer is a multidimensional phenomenon and identify six core dimensions of this experience. Notably, the findings of this study suggest that spirituality may have a transformative role within the lives of those living with terminal cancer. Participants in the empirical study maintained diverse views of spirituality and these findings built upon those of the meta-synthesis highlighting the wide expression of spirituality as while some participants did not exclusively focus on religion or faith at end of life, they found that engaging in spiritual practices had a transformative impact on other related dimensions of this experience.

While living with terminal cancer, participants in this study focused upon '*Recovering Control in Uncertain Times'*, as while they inevitably lost control over some aspects of their lives, they regained control over other aspects of their lives by reframing their expectations of life and acknowledging that their span of control had changed since their diagnosis. In relation to *'Gaining an Increased Awareness of Time'*, participants were able to move beyond experiencing existential angst as they had a renewed sense of appreciation for each day and perceived that they were 'living on borrowed time', which facilitated them in living their lives with meaning and purpose. Despite participants initially struggling with *'Negotiating a Changing Identity'* as they were experiencing a shift between their past and present identities, they were able to re-define themselves through personal growth and development which enabled them to discover new aspects of their true self which they were previously unaware of. Participants reported '*Finding Comfort through Connection'* as they gained a stronger sense of connection with themselves following their diagnosis. Participants also highlighted gaining comfort through their sense of connection to God or a higher power, and with nature and the world around them which helped them to cope with their illness. In relation to *'Navigating the Social World'*, participants posited that while they detached from others who were unable to acknowledge their condition, they focused upon cultivating relationships with those who mattered most to them which helped them to live in a more meaningful manner. Participants viewed the experience of terminal cancer as *'Journeying with Hope'* as their experience of hope was dynamic. While at times they felt hopeless about finding a cure, they highlighted that living with hope was important in their lives and helped them to live well with their disease.

The findings of this study provide a unique insight into the dynamic nature of hope as one lives with terminal cancer. These findings advance literature as they suggest that patients may oscillate between states of hopelessness and hopefulness at end of life rather than experience a distinct transition or shift in a unilateral direction from hopelessness to hopefulness. These findings offer novel insights into the experience of hope from the perspective of terminal cancer patients as hope is dynamic by nature and hence, terminal cancer patients travel across the spectrum of hope along their terminal cancer journey. Further, the results of this study suggest that hope is a diverse concept in the lives of terminal cancer patients and can mean many things to patients across the terminal cancer trajectory. Based on the findings of this study, hope can be an abstract belief for participants, it can also be an appreciation held by participants of future possibilities that could come to pass (while remaining cognisant of limitations) or it can be a way of strategising specific goals or milestones within the lives of participants as they look to the future with positivity. These findings suggest that existing theories of hope need to be extended to cater for the diverse meanings of hope that may be held by participants in different contexts, specifically living with terminal cancer.

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Appendices

Appendix A - ENTREQ File

No.	Item	Description	Reported in Section
1.	Aim	The aim of this review was to examine spirituality as experienced by individuals living with terminal cancer.	2.1.
2.	Synthesis	Thematic synthesis was used in this meta-synthesis.	2.3.6.
3.	Approach to searching	The search was pre-planned with specific search strategies drafted for each database searched.	2.3.1.
4.	Inclusion criteria	Articles were selected for inclusion within the systematic review if they (1) were empirical studies published in English from 1st March 2009 to 12th of March 2022; (2) included adults of 18 years of age or older with a terminal cancer diagnosis; (3) included qualitative data relating to spirituality and spiritual perspectives (and concepts such as, but not limited to: meaning making, existential distress, transcendence, religious perspective, sacred connections and personal growth) from a patient's perspective. Mixed methods, intervention or quantitative studies with open-ended questions were included if qualitative data were reported separately.	2.3.2.
5.	Data sources	Six databases (PubMed, PsycINFO, CINAHL, Embase, Medline and Web of Science) that were deemed most relevant for this topic were searched. The final search was conducted on the 12th of March 2022, examining articles from March 2009 – March 2022.	2.3.1.
6.	Electronic search strategy	Supplementary File B describes the search strategies for each of the databases searched.	Appendix B.

No.	Item	Description	Reported in Section
7.	Study screening methods	Following the exporting of searches from each database and subsequent removal of duplicate studies in Zotero, the remaining titles and abstracts were imported into systematic review software Covidence. A two-stage screening and full text review process was undertaken: Stage 1. Two reviewers (LH, EB or AD) screened the titles and abstracts of included studies independently. Stage 2. Papers deemed as eligible from stage 1 were sourced as full texts and independently assessed for inclusion by LH and EB or AD. Any disputes or discrepancies relating to the above were resolved through consensus. However, two other independent reviewers (SD, PG) were available for discussions to resolve any conflicts that were unable to be resolved.	2.3.3.
8.	Study characteristics	Table 1 represents the characteristics of included articles (author, year, country, aim of study, sample, age range, type of cancer, setting, data collection method and analytical approach of the studies).	Table 2.1.
9.	Study selection results	A PRISMA flow diagram represents the selection process and included studies. 6151 studies were identified from database searching. Following the removal of 1974 duplicates, the titles, and abstracts of 4177 articles were screened for eligibility. Following this phase, 401 full articles were reviewed against the pre-determined inclusion and exclusion criteria. Thirty-seven studies met the inclusion criteria and were included in the meta-synthesis.	Figure 2.1.
10.	Rationale for appraisal	The Critical Appraisal Skills Programme (CASP) was adhered to when appraising the methodological quality of the included studies. Each study was assessed in line with the ten questions on the CASP checklist for qualitative research. Studies that met the criteria were included in the meta-synthesis.	2.3.5., 2.4.2., 2.5.

No. Item	Description	Reported in Section
11. Appraisal items	The Critical Appraisal Skills Programme (CASP) was adhered to when appraising the methodological quality of the included studies.	2.3.5.
12. Appraisal process	All included studies were individually assessed by LH and EB or AD using the qualitative checklist examining methodological quality across 10 items including results; methodology; research design; recruitment strategy; data collection; ethical considerations; and data analysis. Reviewers screened and rated each study using yes, no or can't tell based on each checklist item in accordance with CASP.	2.3.5.
13. Appraisal results	The results from the CASP quality appraisal are shown in supplementary file C.	Table 2.2.
14. Data extraction	The following data was extracted for each included study: author(s); country of study; aims of study; sample size; age range; setting; data collection method; and analytical approach.	2.3.4.
15. Software	The portions of the results and findings sections of the included studies that were relevant to the aims of this review were extracted and entered into NVivo 12 software for data analysis	2.3.6.
16. Number of reviewers	Three reviewers (in pairs of two for each round) were involved in the screening and selection of included studies. Two further reviewers were available for discussions to resolve any conflicts that were unable to be resolved.	2.3.3.

No. Item	Description	Reported in Section
17. Coding	Thematic synthesis was utilised in this qualitative meta-synthesis. The data was thematically synthesised using a three-stage framework; firstly, the line-by-line coding of relevant data; secondly, descriptive themes which remain close to the themes identified in the primary studies were developed according to patterns across the codes; and lastly, the development of analytical themes which go beyond the themes identified in the primary studies to produce a superior level of conceptual understanding and identify new concerns or recommendations relating to the topic being studied.	2.3.6.
18. Study comparison	Studies were compared during the coding phase and similar findings were coded into descriptive and analytic themes within and across different studies in line with thematic synthesis.	2.3.6.
19. Derivation of themes	In line with thematic synthesis, descriptive themes which remain close to the themes identified in the primary studies were developed according to patterns across the codes. Following this, the development of analytical themes which go beyond the themes identified in the primary studies to produce a superior level of conceptual understanding and identify new concerns or recommendations relating to the topic being studied.	2.3.6.
20. Quotations	Table 3 provides illustrative quotes from the studies included in this meta-synthesis.	Table 2.4.
21. Synthesis output	Table 2 provides the synthesis output by presenting both analytic and descriptive themes.	Table 2.3.

Appendix B - Meta-synthesis Search Strategies

PubMed:

S1: (“Neoplasm* Metastasis” [MeSH] OR "Incurable Cancer" OR "Terminal Cancer" OR "Advanced Cancer" OR "Malignant Neoplasm" OR "Metastas*" OR "Neoplasm Metastas*” OR "High Grade Glioma" OR "Cancer Recurrence" OR "Cancer Progression")

S2: (“Spirituality”[MeSH] OR “Religion”[MeSH] OR “Existentialism”[MeSH]) OR ("Spirit*" OR “Spiritual Wellbeing” OR "Spiritual Distress" OR "Spiritual Pain" OR “Religio*” OR "Existential*” OR "Meaning" OR "Liminality" OR "Faith" OR “Death Anxiety” OR “Transcend*”)

S3: (“Qualitative Research”[MeSH] OR “Qualitative” OR “Narration” OR “Ethnograph*” OR “Phenomenol*” OR “Ethnonurs*” OR “Grounded Theor*” OR “Purposive Sample” OR “Hermeneutic*” OR “Heuristic*” OR “Semiotics” OR “Lived Experience*” OR “Narrative*” OR “Life Experience*” OR “Cluster Sample” OR “Action Research” or “Observational Method” OR “Content Analysis” OR “Thematic Analysis” OR “Constant Comparative Method” OR “Field Stud*” OR “Fieldwork” OR “Field Work” OR “Key Informant” OR “Theoretical Sample” OR “Discourse Analysis” OR “Focus Group*” OR “Interview*” OR “Discussion*” OR “Ethnological Research” OR “Ethnomethodolog*” OR “Mixed Model*” OR “Mixed Design*” OR “Multiple Method*” OR “Multimethod*” OR “Triangulat*”)

S4: S1 AND S2 AND S3

PsycInfo:

S1: ("Terminal Cancer"[MeSH] OR “Metastasis” [MeSH] OR "Incurable Cancer" OR "Advanced Cancer" OR "Malignant Neoplasm" OR "Metastas*" OR "Neoplasm Metastas*” OR "High Grade Glioma" OR "Cancer Recurrence" OR "Cancer Progression")

S2: (“Spirituality”[MeSH] OR “Religion”[MeSH] OR "Existentialism"[MeSH] OR "Spirit*” OR "Spiritual Wellbeing" OR "Spiritual Distress" OR "Spiritual Pain" OR “Religio*” OR "Existential*" OR "Meaning" OR "Liminality" OR "Faith" OR “Death Anxiety” OR “Transcend*”)

S3: (“Qualitative Methods”[MeSH] OR “Qualitative” OR “Narration” OR “Ethnograph*” OR “Phenomenol*” OR “Ethnonurs*” OR “Grounded Theor*” OR “Purposive Sample” OR “Hermeneutic*” OR “Heuristic*” OR “Semiotics” OR “Lived Experience*” OR “Narrative*” OR “Life Experience*” OR “Cluster Sample” OR “Action Research” or “Observational Method” OR “Content Analysis” OR “Thematic Analysis” OR “Constant Comparative Method” OR “Field Stud*” OR “Fieldwork” OR “Field Work” OR “Key Informant” OR “Theoretical Sample” OR “Discourse Analysis” OR “Focus Group*” OR “Interview*” OR “Discussion*” OR

“Ethnological Research” OR “Ethnomethodolog*” OR “Mixed Model*” OR “Mixed Design*” OR “Multiple Method*” OR “Multimethod*” OR “Triangulat*”)

S4: S1 AND S2 AND S3

Embase:

S1: (“Malignant Neoplasm”/exp OR “Terminal Cancer” OR "Incurable Cancer" OR “Advanced Cancer” OR “Malignant Neoplasm” OR “Metastas*” OR “Neoplasm Metastas*” OR “High Grade Glioma” OR “Cancer Recurrence” OR “Cancer Progression”)

S2: (“Religion”/exp OR “Existentialism”/exp OR ‘Spirit*” OR “Spiritual Wellbeing” OR “Spiritual Distress” OR “Spiritual Pain” OR “Religio*” OR “Existential*” OR “Meaning” OR “Liminality” OR “Faith” OR “Death Anxiety” OR “Transcend*”)

S3: (“Qualitative Research”/exp OR “Qualitative” OR “Narration” OR “Ethnograph*” OR “Phenomenol*” OR “Ethnonurs*” OR “Grounded Theor*” OR “Purposive Sample” OR “Hermeneutic*” OR “Heuristic*” OR “Semiotics” OR “Lived Experience*” OR “Narrative*” OR “Life Experience*” OR “Cluster Sample” OR “Action Research” or “Observational Method” OR “Content Analysis” OR “Thematic Analysis” OR “Constant Comparative Method” OR “Field Stud*” OR “Fieldwork” OR “Field Work” OR “Key Informant” OR “Theoretical Sample” OR “Discourse Analysis” OR “Focus Group*” OR “Interview*” OR “Discussion*” OR “Ethnological Research” OR “Ethnomethodolog*” OR “Mixed Model*” OR “Mixed Design*” OR “Multiple Method*” OR “Multimethod*” OR “Triangulat*”)

S4: S1 AND S2 AND S3

Medline:

S1: (“Neoplasm Metastasis”[MeSH] OR "Terminal Cancer" OR "Incurable Cancer" OR "Advanced Cancer" OR "Malignant Neoplasm" OR "Metastas*" OR "Neoplasm Metastas*” OR "High Grade Glioma" OR "Cancer Recurrence" OR "Cancer Progression")

S2: (“Spirituality”[MeSH] OR "Spirit*" OR "Spiritual Wellbeing" OR "Spiritual Distress" OR "Spiritual Pain" OR “Religio*” OR "Existential*” OR “Meaning” OR “Liminality” OR “Faith” OR “Death Anxiety” OR “Transcend*”)

S3: (“Qualitative Research”)[MeSH] OR “Qualitative” OR “Narration” OR “Ethnograph*” OR “Phenomenol*” OR “Ethnonurs*” OR “Grounded Theor*” OR “Purposive Sample” OR “Hermeneutic*” OR “Heuristic*” OR “Semiotics” OR “Lived Experience*” OR “Narrative*” OR “Life Experience*” OR “Cluster Sample” OR “Action Research” or “Observational Method” OR “Content Analysis” OR “Thematic Analysis” OR “Constant Comparative Method” OR “Field Stud*” OR “Fieldwork” OR “Field Work” OR “Key Informant” OR “Theoretical Sample” OR “Discourse Analysis” OR “Focus Group*” OR “Interview*” OR “Discussion*” OR

"Ethnological Research" OR "Ethnomethodolog*" OR "Mixed Model*" OR "Mixed Design*" OR "Multiple Method*" OR "Multimethod*" OR "Triangulat*")

S4: S1 AND S2 AND S3

Cinahl:

S1: ("Neoplasm Metastasis"[MeSH] OR "Terminal Cancer" OR "Incurable Cancer" OR "Advanced Cancer" OR "Malignant Neoplasm" OR "Metastas*" OR "Neoplasm Metastas*" OR "High Grade Glioma" OR "Cancer Recurrence" OR "Cancer Progression")

S2: ("Spirituality"[MeSH]" OR "Spirit* OR "Spiritual Wellbeing" OR "Spiritual Distress" OR "Spiritual Pain" OR "Religio*" OR "Existential*" OR "Meaning" OR "Liminality" OR "Faith" OR "Death Anxiety" OR "Transcend*")

S3: ("Qualitative Studies"[MeSH] OR "Qualitative" OR "Narration" OR "Ethnograph*" OR "Phenomenol*" OR "Ethnonurs*" OR "Grounded Theor*" OR "Purposive Sample" OR "Hermeneutic*" OR "Heuristic*" OR "Semiotics" OR "Lived Experience*" OR "Narrative*" OR "Life Experience*" OR "Cluster Sample" OR "Action Research" or "Observational Method" OR "Content Analysis" OR "Thematic Analysis" OR "Constant Comparative Method" OR "Field Stud*" OR "Fieldwork" OR "Field Work" OR "Key Informant" OR "Theoretical Sample" OR "Discourse Analysis" OR "Focus Group*" OR "Interview*" OR "Discussion*" OR "Ethnological Research" OR "Ethnomethodolog*" OR "Mixed Model*" OR "Mixed Design*" OR "Multiple Method*" OR "Multimethod*" OR "Triangulat*")

S4: S1 AND S2 AND S3

Web of Science (limited to Social Science Citation Index):

S1: TS=("Terminal Cancer" OR "Incurable Cancer" OR "Advanced Cancer" OR "Malignant Neoplasm" OR "Metastas*" OR "Neoplasm Metastas*" OR "High Grade Glioma" OR "Cancer Recurrence" OR "Cancer Progression")

S2: TS=("Spirit*" OR "Spiritual Wellbeing" OR "Spiritual Distress" OR "Spiritual Pain" OR "Religio*" OR "Existential*" OR "Meaning" OR "Liminality" OR "Faith" OR "Death Anxiety" OR "Transcend*")

S3: TS=("Qualitative Research" OR "Qualitative" OR "Narration" OR "Ethnograph*" OR "Phenomenol*" OR "Ethnonurs*" OR "Grounded Theor*" OR "Purposive Sample" OR "Hermeneutic*" OR "Heuristic*" OR "Semiotics" OR "Lived Experience*" OR "Narrative*" OR "Life Experience*" OR "Cluster Sample" OR "Action Research" or "Observational Method" OR "Content Analysis" OR "Thematic Analysis" OR "Constant Comparative Method" OR "Field Stud*" OR "Fieldwork" OR "Field Work" OR "Key Informant" OR "Theoretical Sample" OR "Discourse Analysis" OR "Focus Group*" OR "Interview*" OR "Discussion*" OR

“Ethnological Research” OR “Ethnomethodolog*” OR “Mixed Model*” OR “Mixed Design*” OR “Multiple Method*” OR “Multimethod*” OR “Triangulat*”)

S4: S1 AND S2 AND S3

Appendix C - Recruitment Poster

We are looking for people to take part in a research study involving interviews and want to speak to you.

Are you living with advanced cancer?

What is this research about?

We want to learn about your experiences at this time in your life. We hope that this will help us to come up with new ways and guidelines to care for and support people with advanced cancer in the future.

What is involved?

You will be asked to take part in a conversational interview about your experience of living with advanced cancer. It will take approximately 60 - 90 minutes. Interviews will be conducted in a flexible manner (in-person or by phone/video call) and will be audio recorded only.

Interested in taking part?

For more information or to register for participation, please contact lucy.haydensmyth8@mail.dcu.ie

This research is being conducted in the School of Psychology in Dublin City University in conjunction with the Irish Research Council and Breakthrough Cancer Research.

DCU
Ollscoil Chathair
Bhaile Átha Cliath
Dublin City University

breakthrough
CANCER RESEARCH

IRISH RESEARCH COUNCIL
An Chomhairle um Thaighde in Éirinn

Appendix D - Semi-structured Interview Guide

- Tell me about yourself.

Living with Dying: Can you tell me about what it's like to live with cancer that can't be cured.

- Prompts:
  - Tell me about how your life has changed during this experience.
  - How do you feel about these changes?
  - What has been helpful to you in coping with the illness/what resources have you drawn upon?

Changed Perspectives: What aspects of your life are most important to you?

- Prompts:
  - Can you tell me about how living with cancer has affected your relationships with your family/friends?
  - What kind of questions do you ask yourself these days?
  - What are your greatest concerns now?

Meaning Making: What gives you meaning and purpose in life?

- Prompts:
  - Have your faith or beliefs influenced how you have coped with your illness?
  - Tell me about hope and what it means to you.
  - Has having cancer changed how you cope with things in your life?
  - Tell me about what brings you peace.

End of Life: How do you wish to live for the rest of your life?

- Prompts:
  - To what extent do you believe that your fate is in the hands of God or a higher power?
  - How do you picture your final days of life?
  - What legacy would you like to leave behind?

Appendix E - Demographic Questions

1. What gender do you identify as?
2. What is your current age?
3. What was the nature of your initial diagnosis (terminal/metastatic/benign)?
4. What type of cancer were you diagnosed with?
5. How long has it been since your diagnosis?
6. What is your marital status?

Appendix F - Consent Form

Consent Form

Living and Dying Well –

An Investigation of Being Towards Death Among Terminal Cancer Patients.

Principal Investigators: Ms Lucy Hayden | Dr Simon Dunne | Prof Pamela Gallagher
Researcher: Lucy Hayden | **Email:** lucy.haydensmyth8@mail.dcu.ie

- I confirm that I have read the attached Plain Language Statement, and that I understand the information provided therein and have had time to consider this information.
  Yes No

- I confirm that I have been diagnosed with terminal cancer (with a prognosis of up to 12 months).
  Yes No

- I confirm that I am 18 years of age or older.
  Yes No

- I understand that my participation in this study is completely voluntary, and that I am free to withdraw at any time, without giving any reason and without being penalised for doing so.
  Yes No

- I understand that the data collected as part of this study will be kept entirely confidential and is for use in a postgraduate research project.
  Yes No

- I understand that this data may also be used for the purpose of peer reviewed articles, academic reports and/or conference presentations.
  Yes No

- I understand that in the case of online interviews through applications such as Zoom, there will be no video-recording of the interview.
  Yes No

- I understand that data will be audio-recorded only and the audio recording will be stored securely.

Yes No

- I understand that only the postgraduate researcher and supervising researchers will have access to the audio data and interview transcript and the examiners will have access to only the de-identified interview transcript.
  Yes No

- I give my consent to participate in this research.
  Yes No

Participant's Signature / E-signature:______________________________________

Date:____________________________________

____

Appendix G - Risk Management Protocol

Risk Management Protocol

Living and Dying Well –

An Investigation of Being Towards Death Among Terminal Cancer Patients.

Principal Investigators: Ms Lucy Hayden | Dr Simon Dunne | Prof Pamela Gallagher
Researcher: Lucy Hayden | **Email:** lucy.haydensmyth8@mail.dcu.ie

Protocol: Responding to participant distress and minimising interviewer safety risks.

Introduction: In the event that participants feel distressed, measures will be taken to respond appropriately. These measures relate to the conduct of interviews. Measures to maximise interviewer safety will also be outlined in the protocol below.

Responding to interviewee distress

- The researcher will agree on a time and venue that is comfortable for potential participants.
- All potential participants will be informed of their right to withdraw from the study at any stage; during the interviews or after the interview has been completed. This information will be communicated in the plain language statement and verbally prior to the interview beginning.
- At the start of each interview, the researcher will spend some time engaging in 'problem-free talk' that helps participants to feel comfortable in the interview situation and to build some trust with the researcher. Once this trust has been established, the researcher will also check the subjective comfort of participants, remind them of their right to withdraw and seek their agreement on their readiness to proceed.
- The researcher will check the comfort level of participants throughout, and remind them that they are not obliged to answer any question.
- If the researcher observes signs of emotional distress for the participant (e.g. crying), the researcher will ask the participant if they wish for the audio recording to be stopped or if they would like the researcher to move on to a different question. If the participant wishes to stop the interview at this stage, the researcher will give the participant the option to withdraw from the study.
- If a participant becomes unduly distressed during the interview, the researcher and participant will also seek agreement upon 'what happens next'. This will include asking whether the participant would like the researcher to contact any additional supports on their behalf. The researcher will not seek additional support on the participant's behalf without such agreement, unless there is an extreme situation whereby the participant's safety is in doubt, and no such agreement can be reached. In this extreme situation the researcher will call the emergency services.
- All participants will be provided with the contact details for various support services (Irish Cancer Society, ARC, relevant counselling services, freephone hotlines etc) on the

plain language statement that they can contact if they wish to discuss any negative emotions as a result of their participation in the study.

Ensuring researcher safety

The measures outlined below will be put in place when conducting face-to-face in-person interviews with participants across all locations. Should governmental restrictions regarding social distancing and the management of COVID-19 remain in place at the time of data collection, all interviews will take place via a telecommunications application remotely. Should public health guidelines suggest that it is safe to conduct interviews in a socially distant manner, interviews will be conducted in keeping with the recommended public health guidelines at that time. For all off-site interviews, the researcher will ensure she has downloaded the DCU SAFEZONE App and in the event of an emergency will activate the red “Emergency” button

In a participant’s home

The following measures have been identified to minimise interviewer safety risks when interviews are conducted in the participant’s home:

- For all home visits, the researcher will send a text message to a member of the supervisory team immediately before she enters the participant’s home. She will identify the exact address of the participant’s home and the time of the interview. She will check-in on the DCU SafeZone App and share her location with the DCU security team before the interview commences. The check-in timer will be set for the duration of the interview.
- Be vigilant for signs that the participant is in an unfit state to perform the interview before entering their home. In the event that the individual appears to be unfit for participation, the researcher will withdraw from the situation, indicate that they will be in touch at a later stage to re-arrange the interview.
- Be mindful of any potential safety risks upon entering the participant’s home. The researcher will also make note of the most accessible route of escape open to them. In the event that the researcher encounters a risk to their safety, they will extricate themselves from the premises via the exit route identified.
- Immediately following a home visit, the researcher will send a text message to the supervisor/principal researcher to indicate that the interview is finished. She will also check-out on the DCU SafeZone App when the interview is completed.
- In the event that the supervisor/principal researcher has not received this second text message after two hours, he will attempt to contact the researcher directly. Similarly, If the researcher does not check-out, the SafeZone application will alert DCU security services and a response team will check the location of the researcher.

In a neutral venue or DCU

The following measures have been identified to minimise interviewer safety risks when interviews are conducted in a neutral venue (a café, public area etc):

- The researcher will send a text message to the supervisory team to inform him where and when the interview is taking place at least 24 hours in advance of the interview.

- She will check-in on the DCU SafeZone App and share her location with the DCU security team before the interview commences. The check-in timer will be set for the duration of the interview.
- The researcher will ensure that the location is appropriate for conducting an interview (e.g. that it is not too noisy or crowded).
- Following completion of the interview, the researcher will inform the principal/supervising researcher that the interview is finished via text message. She will also check-out on the DCU SafeZone App when the interview is completed.
- If supervising researcher does not received confirmation of the conclusion of the interview, they will attempt to contact the researcher directly via mobile phone and will follow-up on this as necessary. Similarly, If the researcher does not check-out, the SafeZone application will alert DCU security services and a response team will check the location of the researcher.

Risk Management Protocol for Online Interviews
These measures will be adhered to when interviews are conducted online, and aim to ensure data protection, and to minimise the potential distress for interviewees.

- All participants will have the option to complete their interview online should it be the most convenient or comfortable option for them. Alternatively, they can opt to complete the interview face-to-face (subject to COVID-19 governmental restrictions), or over a phone call.
- Participants who choose to participate in an interview via an online video platform will be offered the option of doing so using Zoom. The plain language statement (Appendix C) outlines the encryption and security features of each platform, in line with advice from the DCU Data Protection Unit.
- Participants who choose to complete the interview remotely can schedule the interview for a time that is convenient for them, and can select a location that is comfortable for them. The participant will be informed on the plain language statement and at the beginning of each interview that they can stop or withdraw from the interview at any time, without penalty.
- The principal researcher will be in a suitable location (such as a private office or quiet secure room) at her end of the call.
- The data that will be recorded as part of the data collection process will be limited to audio recordings.
- The distress protocol outlined above will also be implemented for online interviews.

Appendix H - Plain Language Statement

Plain Language Statement

Living and Dying Well –
An Investigation of Being Towards Death Among Terminal Cancer Patients.

Principal Investigators: Ms Lucy Hayden | Dr Simon Dunne | Prof Pamela Gallagher
Researcher: Lucy Hayden | **Email:** lucy.haydensmyth8@mail.dcu.ie

Note: This research forms the basis of a postgraduate PhD thesis. This project is funded by the Irish Research Council with Breakthrough Cancer Research through the Enterprise Partnership Scheme (EPSPG/2020/402).

Please read the information sheet and think about whether you wish to take part in the study. The sheet tells you about the study and what you will have to do if you decide to take part. Please feel free to discuss the contents with us, or anyone else you wish.

What is the study about?

We would like you to share your experience of living with cancer that can't be cured and what it means for you. We are interested in understanding your concerns, how you feel you are coping while living with late stage cancer and what's most important to you now. The findings of this study may be used to inform and develop services that will help terminal cancer patients and their families to live better through understanding what it means to live with cancer that can't be cured.

How do I know if I am eligible to take part?

You are eligible to take part if you have been diagnosed with terminal cancer (with a prognosis of up to 12 months). You must be at least 18 years of age and in a position to give informed consent to participate and with sufficient spoken English to speak about your experience in an interview. We need people like you to tell us the concerns you have while living with terminal cancer. In order for the research to be successful, and produce reliable results, we need as many people as possible to agree to take part. For this reason, we would greatly appreciate your participation.

What will I have to do if I agree to take part?

If you agree to participate, you will be asked to take part in an interview and the researcher will contact you to arrange the details of this interview. The interview will be arranged for a time convenient for you. We estimate that the interview will take approximately sixty to ninety minutes, but there is no time limit on the length of interviews. Our researcher will start by asking for some basic information about yourself and then go on to ask you questions about your experience of living with terminal cancer and what this means for you. You can also bring up any issues that you think are important.

If you agree to complete the interview in a face-to-face setting, the researcher will audio-record the interview on an audio recording application on a smartphone. This is so we can extract all of the important information from the interview. If Covid-19 related social distancing measures remain in place at the time of data collection, socially distanced interviews adhering to healthcare guidelines may be conducted. This will include the wearing of face masks, a distance of two metres will be kept between the researcher and the interviews will take place in a suitably ventilated room.

If you wish to complete the interview remotely, we will offer you the option to do so using Zoom. This application offers end-to-end encryption services and is very secure. An audio file only of the interview will be recorded. This will be kept in a secure location and will only be accessible to members of the research team. Everything you tell us will be treated in the strictest confidence.

Do I have to take part?

No. Your participation in this study is entirely voluntary - it is up to you to decide whether or not you wish to take part. Even if you decide to take part now, you are still free to withdraw at any time in the future without giving a reason. Should you wish to withdraw from the study, there will be no penalty and no effect on your treatment in any way. If any aspect of the interview makes you feel unduly uncomfortable or distressed, you can ask to stop the interview at any time and without giving any reasons for stopping the interview. Alternatively, you can request for the researcher to move on to a different question if you are not comfortable answering a particular question.

What are the possible benefits and risks in taking part?

There is no direct benefit to you from taking part and you will not be paid. The study will take up some of your time. We hope that the information we get from the study can be used to identify what kinds of additional advice, information or services that are needed to better support people living with terminal cancer. It is also possible for you to request a summary of the research or a transcript of the interview from the researcher on the details provided below. It is not anticipated that there would be any risks in taking part in the study. However, if you experience any emotional upset as a result of the issues raised during the interview, or at a later stage, you can contact the Irish Cancer Society’s Cancer Nurseline on freefone 1800 200 700.

Data Protection Notice

All of the information you provide will be stored in a secure location at Dublin City University. Your information will be kept safe and secure and treated with strict confidence in accordance with General Data Protection Regulations (GDPR). Your personal details and views will not be revealed to anyone outside of the study team and your name will not be identified in any reports or publications arising from the study. The data will be used primarily for the purpose of a PhD thesis and may be used as the basis of published academic reports or conference proceedings.

However, all data reported through these channels will have all participants’ details de-identified. Consent forms will be stored in a locked filing cabinet on the DCU campus that will only be accessible to the research team. All of the interview transcripts and audio files will be stored securely in a password-protected file on the researcher’s password-protected google drive account. All data will be retained for a period of five years following completion of the study from final publication of the data. After this period, destruction will take place in line with DCU research policies.

Data will be available to the principal investigators of this study only. In addition, examiners may request de-identified transcripts of interviews but will not have access to audio files. In rare circumstances, the researchers may be asked to provide information about specific individual participants that partake in this research, under law. Confidentiality of information can only be protected within the limitations of the law - i.e., it is possible for data to be subject to subpoena, freedom of information claim or mandated reporting by some professions.

All participants have the right to erase their data on request or object to processing of their data by withdrawing from the study, without penalty. However, participants will not be given the opportunity to amend or review transcripts of their interview as we wish to capture their initial thoughts and feelings in response to questions to provide the truest possible reflection. If you wish to withdraw from the study at any point prior to submission of the PhD thesis or associated published studies, your information will be removed from the study and all electronic and data files will be destroyed. After submission, it will not be possible to remove your information from the study.

Data Controller: Dublin City University

DCU Data Protection Officer: Mr. Martin Ward | Email: data.protection@dcu.ie | Ph: 01 7005118

Ethical approval

This study has received ethical approval from the Dublin City University Research Ethics Committee. If you wish to contact an independent person in relation to your concerns about this study, please contact: The Secretary, Dublin City University Research Ethics Committee, c/o Research and Innovation Support, Dublin City University, Dublin 9. Tel 01-7008000, e-mail rec@dcu.ie.

Where can I find out more?

If you have any questions that have not been answered here or would like more information about this study, please contact the principal investigator, Lucy Hayden. E-mail: lucy.haydensmyth8@mail.dcu.ie. Telephone: 01 7006448.

Thank you for taking the time to consider taking part in this study, we greatly appreciate your participation.

Appendix I - Data Analysis Template

Analysed Patient Transcript: ‘Patient Name’		
Experiential Statements	***Transcript***	***Exploratory Notes***

Appendix J - Data Analysis Sample

Analysed Patient Transcript: ‘Adele’ (Page 4-7 of analysis)		
Experiential Statements	***Transcript***	***Exploratory Notes***
Feeling significant shock after diagnosis Feeling a sense of not belonging in new world Feeling distressed at changing identity to being a patient Feeling isolated from others after diagnosis Feeling distressed over living with uncertainty of future (health, prognosis) Identifying the uniqueness of each cancer journey	I think at the beginning, like, I feel **I removed myself from situations. So I was the person everybody was buzzing around, but I was somewhere outside that body experience. I think that's just how I was getting through it. I was just being the person in the places and I was in shock. Like, I was in shock for an awful long time. And feeling I didn't belong, you know when you go inside the hospital.** I've never been a patient in a hospital. **So like, all of a sudden, I'm a patient with a chart. And a medical record number. And somebody’s calling my name to do something to me that I don’t have a great understanding of. Yeah, so it's traumatic in many, many ways.** And then, because it was stage four, I wasn't going through the chemotherapy, the radiotherapy, where you get to meet lots of cancer patients going through similar things as you. So I wasn't having any of that. **So the isolation was huge as well, because I wasn’t sitting beside anybody with my story**. **So there was no outlet for me to talk about it. And understand that there may be other people out there living with same thing as me. I just thought I was on my own, the only person there living with this, and I thought, how long? How long am I gonna live for? Because there is nobody out there with stage four. So I really thought from the very beginning that I was doomed really.** But I think looking back now, I realise I dealt with it in my own way. And I don't think anybody can kind of guide you through how to deal with it. **I think everybody is very unique, and that uniqueness comes down to your diagnosis as well and where it has spread to and how far it’s spread and how gruesome your treatment is going to be from the very beginning, w**hether you are straight on chemotherapy.	Coping with impact of diagnosis: ‘outside the body experience,’ Feeling a sense of shock Hospital: feeling like she doesn’t belong Identity: suddenly being ‘a patient with a chart’ and feeling a sense of trauma Sense of isolation: Stage 4 is different from other patients, so not meeting others who were having similar experience Uncertainty over time left / prognosis
Having preconceptions of how cancer experience might look	And I think part of that understanding was, if you’re a cancer patient, you’d go straight on to chemotherapy. **And the fact that I was just sent home with tablets, I couldn’t understand that as well. Like I thought ‘oh my**	Expecting chemotherapy, but due to late stage cancer, not being offered that – shock and worry

Feeling disappointed and worried about difference with own experience Finding coping most difficult Needing to be asked about emotional health Needing help with coping Feeling emotional distress and being unable to cope with emotional difficulties Needing emotional support from HCPs (services) but not receiving any support Physical needs being supported by HCPs **Night:** being unable to manage/regulate thoughts at night, inability to sleep	**God, I’m not even being given the treatments other patients are being given.’ And I’m been sent home with some tablets at stage four. And then of course on the tablets it had ‘compassionate’ and I thought ‘they’re just feeling sorry for me.’ They’re giving me these tablets to go home and how long is this going to work on me? So yeah there’s was an awful lot of things going through your head and the coping element, I think, is probably the most difficult part.** And going in for hospital appointments, **I always remember them asking me physically, how am I? And how's my health? Have I been sick? Or had diarrhoea, if I had any other symptoms? And my answers were always no, but in the back of my head, I was always pleading, please ask me how I’m coping, because I don’t know how I am coping. I don’t know how somebody is supposed to cope with a diagnosis like this. So I know I was having a lot of anxiety, but I'd never experienced anxiety before. So was it anxiety, was I supposed to be feeling the way I was feeling? Were the thoughts that were going through my head proper thoughts? Is this the way I'm supposed to be coping with it? So I just thought, if they just asked me how am I coping, I’d get an opportunity to tell them what's going on in my head. But nobody ever did ask me. So then I thought maybe I'm overplaying the situation. Maybe I'm overthinking it. Maybe I shouldn't be feeling this way. Maybe I should be thinking about going back to work. Maybe I shouldn't be feeling the way I'm feeling. And I said, I was thinking my emotions were wrong. Because nobody was asking me how I was coping with it. So I felt I have to hide my emotions. You know, because I thought maybe this is a natural way to deal with this. Maybe the cancer I've been told I have isn't as bad as I think it is. You know, it led me to misunderstand my position, as well. And I think it might have been helpful for someone just to say ‘how are you coping? We have networks for you to go to, if you feel you need to talk.’ But that wasn’t there.** It just seems to be all the medical end of things and once the medical end was taken care of, which they were, they were taking care of everything, every aspect, my CCs were done, bone scans were done, everything that needed to be done was getting done. And these compassionate tablets, which I understand now, the word compassionate, was there because they weren’t available on the market. But at the time,	Unfortunate name for medication added to worry over life expectancy ‘compassion’ Hospital experience: being asked about physical symptoms but in her head pleading to be asked about emotional/mental coping Never being asked about how she’s coping Worrying about feelings of anxiety, worrying about whether thoughts/feelings were normal Worrying about whether she’s overthinking and whether emotions were wrong Wondering whether situation was as serious as had previously been indicated Wishing for someone to ask ‘how are you coping?’ But it didn’t happen Night time: inability to turn off mind, inability to sleep

Feeling of time stretching out at night Self vs body: being unable to control brain to switch off thoughts Waking up feeling like drowning at night Finding support from others: FB Support group Seeking help in coping with body's inability to rest Learning to give herself permission to be kind to self (self-care) Learning to ask HCP for help with coping Hiding, isolating from others, feeling scared of knowing / not knowing information Feeling scared to seek answers to questions	the word compassionate on a box you're taking home from the hospital had a different meaning for me. I think, yeah, there's a lot in the coping mechanisms. **I think sleeping at night was one of the worst, trying to get to sleep at night, because my mind was… I couldn't turn off my mind. So sleeping was the worst, I literally couldn't sleep actually.** What would you do then, to try and deal with those emotions and worries that came up at night? I felt if I got up, I was going to make the situation worse. **Then the night time stretches on and on and on. So I did lie in bed and I just tossed and turned and I tried to turn my head off. Even if I dozed off, within seconds, I was waking up like I was drowning. So my brain wasn't even allowing me to switch off. That was very visceral.** And because I had never taken tablets in my life, I thought, 'well, I'm not going to take sleeping tablets when I should be asleep. But at one point, I did join an online Facebook group and one girl put in a comment, you know, about being kind to yourself. And I always wondered why people always say **'be kind to yourself.' But she had said 'no, it's not a failure to ask for a sleeping tablet, don't battle it.' If you feel you need sleep, go and ask for it.'** And I just needed that, just her even saying that, I went, **'why am I putting myself through all this difficulty, what am I doing this for because I am not being kind to myself.'** And somehow I think that just her even saying that allowed me to go and ask the doctor for a sleeping tablet. And I don't know why I didn't think this was a normal and natural thing to do. **But somehow I thought I could fight this, I don't need all this intervention or I don't need this help, but maybe it was because I wasn't being told I was allowed to.** Have you developed any ways to cope from the time of diagnosis up to now, in the five years since the diagnosis? Yeah. I know in the very first year, I think I stayed in isolation. **I was like a crab underneath a rock, I just hid because I was petrified; I was petrified of not knowing, I was petrified of knowing too much.** And I	Night: feelings of drowning FB Support Group: 'be kind to yourself' – battling with insomnia and refusing sleeping tablets, shifting to deciding to take them 'it's not a failure…don't battle it' Identity: 'don't take tablets' (resisting help vs accepting help) Feeling the need for permission to ask for help and not battle alone Coping: isolating / hiding herself as a means of coping Feeling 'petrified' – of 'not knowing' vs knowing 'too much' Feeling isolated and alone: not knowing anyone else with stage four

Feeling scared of knowing reality/prognosis but needing to know also Needing to seek out answers and talk to other patients (searching for information) Seeking out cancer patient groups online to find some answers Needing to find a group of others who shared her fate	didn't, because I hadn't got to go talk to anybody with stage four, **I was afraid to seek out stage four, because I thought well surely if people are living with stage four, they're out there saying, 'I'm still alive,' you know.** And so the fact that nobody was doing that, I thought, well, **if I go sit in a group of stage four, and I fail in my mission, then I know I am out there on my own. So sometimes, seeking the answers to your questions can be terrifying. Because you think maybe the answer's going to come back, and it's going to be the negative part of it, and then you're going to have to deal with the reality of that negativity. So in the first year, I just was so petrified, I just stayed quiet**. Then the curiosity began to get in on me. I thought, **I still haven't spoken to anybody with stage four, I need to do this. I need to find out if my life is shorter than I think.** I thought maybe I need to seek more information. But in seeking that information, the only way to do it was to go online. And I ended up on sites reading things I didn't want to read. I didn't want to know all of these statistics. I just wanted to find a support group. I think it was very difficult to find a proper support group. There was a breast cancer support group, where women were going through breast cancer, but they had six months treatment or a year's treatment and then they were moving on, and then getting on with their lives like which is fantastic for them. But that wasn't going to be the future for me.	Afraid to seek out others with similar experiences Terror of seeking answers to questions because of potential negative reality and having to deal with that Seeking/needing answers Needing to speak with others with similar experiences Needing to go online to seek out others / information / support group

Examples of Clustering of Experiential Statements for 'Adele'
Feeling significant shock after diagnosis p.4 Feeling a sense of not belonging in new world p.4 Feeling scared to seek answers to questions p.7 Feeling scared of knowing reality/prognosis but needing to know also p.7 Needing to seek out answers and talk to other patients (searching for information) p.7 Seeking out patient groups to find some answers p.7 Feeling like a stranger in new world p.19 Adapting to living with uncertainty of health in future p.3 Accepting cancer being a part of life p.8 Focusing on being happy instead of being angry p.8 Acceptance of living with uncertainty p.9 Finding it easier to manage uncertainty of future, foreground vs background of mind p.15
Feeling relief of relating to others with similar experiences p.7 Finding a suitable FB group to speak with p.7 Gaining inner confidence to take next step to meet in person group p.7 Finding difficulty in attending in person support group and identifying herself as a cancer patient to others p.7 Gaining insight/information from other cancer patients helps p.7 Only patients understand and share honestly in groups p.12 Difficulties with patient groups: changing faces serve as a reminder of reality of death p.12
Seeing others die provoking worry about whether family is sufficiently prepared for death p.12 Not wanting to burden family with information p.9 Protecting family from having too much knowledge p.9 Preparing family for uncertainty of future (illness) p.9 Sharing broad health information only with family members to protect them p.12 Not needing extended family members to understand about prognosis p.12 Feeling relieved that extended family doesn't understand p.12 Having freedom to live life without discussing realities with family and others p.12 Hiding truth from friends/family p.12

Example of Personal Experiential Theme (PET) for 'Adele':

1. **LOSING AND FINDING CONTROL**

Feeling out of control

Feeling significant shock after diagnosis p.4
'I was somewhere outside that body experience. I think that's just how I was getting through it. I was just being the person in the places and I was in shock. Like, I was in shock for an awful long time.'

Feeling a sense of not belonging in new world p.4
'And feeling I didn't belong, you know when you go inside the hospital. I've never been a patient in a hospital. So like, all of a sudden, I'm a patient with a chart. And a medical record number. And somebody's calling my name to do something to me that I don't have a great understanding of.'

Feeling scared to seek answers to questions p.7
'I was like a crab underneath a rock, I just hid because I was petrified; I was petrified of not knowing, I was petrified of knowing too much.'

Feeling like a stranger in a new unknown world p.19
'Because all of a sudden you're thrown into this world of the unknown and of course, there's going to be emotions you haven't ever experienced before, and you're not going to understand everything that's going on in your head.'

Seeking control

Seeking out patient groups to find some answers p.7
'Maybe I need to seek more information. But in seeking that information, the only way to do it was to go online. And I ended up on sites reading things I didn't want to read. I didn't want to know all of these statistics. I just wanted to find a support group.'

Facing the uncertainty of future head on by gaining insight / information from other cancer patients p.8
'So the uncertainty door is being opened up, because now you're going to know for sure how your future might pan out.'

Taking back control

Gaining a better ability to cope with uncertainty p. 15

‘But I think coping wise, I probably have more ability to cope with the uncertainty, because I am part of that group. And the uncertainty is for sure, there to the forefront of your mind. And it's all the time playing in the background in your mind.’

Accepting cancer being a part of life p.8

‘I think now it is being happy and finding a place in my head where cancer is part of my life. But that quality of life, getting used to the idea that I can live with this in my life, and still smile and be happy and enjoy the things that happen, like grandchildren coming along. And the acceptance that life has changed and accepting that and not being angry about things’

Example of Group Experiential Theme Development Across 10 Participants

THEME: GAINING AN INCREASED AWARENESS OF TIME: *'ALL OF A SUDDEN, YOU'RE TOLD 'THE CLOCK IS TICKING'*

- **Subtheme: Feeling Existential angst: '*It [Cancer] haunts me most of every day'***

Name:	**Illustrative Extracts:**
Linda / Feeling existential distress	'As human beings, even if you didn't have a cancer diagnosis, you do not know when you're going to die. […] Once you're given a [terminal] diagnosis, that all changes, because all of a sudden, you're told the clock is ticking.' [Page 2]
	'I wake up literally every day. [My awareness of death] is in my mind, and on my mind. It haunts me most of the day […]. I mean, it's kind of like I'm existing, you have no choice.' [Page 2]
Darragh / Feeling existential distress	'Everybody else thinks you look fantastic…But at the same time, there's a loud ticking noise going on in the back of your head…[Having] this voice in the back of your head […] that says it's going to kill you. It's always there, it whispers quietly in the back of your head.' [Page 53]
	'There's absolutely no way of knowing what's going to happen. […] You become a little bit more aware of your mortality every time there's scans and meeting your oncologist comes around, because in a five-minute conversation, he could change your life completely.' [Page 18]
	'There are times when you really do feel really, really dark, […] the lights have gone out, and the room's gotten cold. And you know, you can feel fingers, cold fingers on your shoulder. […] And it's very easy to drift into that mindset, and it's difficult to get out of.' [Page 56]
Kiera / Existential distress	'There was a lot of stuff that was very emotional, even Mother's Day, we went out for a meal, my birthday. I had a complete meltdown on my birthday, much to everybody's surprise. But I was convinced that it was my last birthday.' [Page 11]
Danielle / Distress about death	'Like, I've had times, particularly it seems I wake up in the dead of night, at around three or half three and it's pitch dark and silent. […] That's when it tends to hit me. That hour of the night. And I'll have a little cry for myself, […] and then I'll go back to sleep.' [Page 44]

Adele / Distress about death	‘The night-time stretches on and on and on. […] Even if I dozed off, within seconds, I was waking up like I was drowning. So, my brain wasn't even allowing me to switch off. That was very visceral.’ [Page 6]

- **Valuing Time as currency: ‘*I value my time more than I value anything else’***

Name:	**Illustrative Extracts:**
Layla / Prioritising time	‘I value my time more than I value anything else. I don’t care how much money I have or material things I have or any of that stuff. Like, if I've got time to enjoy life and do the things that I want to do, then that's the most important thing to me.’ [Page 2]
Adele / Prioritising time to live	‘For me, it's not seeking out the best holiday or the most expensive car, or to have flash clothes. It's just being able to get up every day on your own, have your breakfast, go for a walk, […] it's just about being able to get about my little life, my little quiet life.’ [Page 16]
Darragh / Valuing time	‘I do try and find moments of peace and happiness. […] And every now and again you just sit out [in garden] […] and I think in terms of what's important to me, is trying to find opportunities for those moments. […] Taking the dogs out for a walk is something I enjoy doing.’ [Page 18]
Ben / Prioritising time	‘A lot of people worry about stupid material things in life. Things that don’t matter. Material things don’t matter to me in life, it’s about enjoying it. […] For me, life is *now* about creating memories.’ [Page 5]
Joanne / Valuing the brief time available	‘We're only passing through here for a short period of time. And you know, whatever you have, if you can share what you have, do that and show a little bit of kindness to somebody every day.’ [Page 24]
Diana / Valuing time	‘As I'm living at the moment, I'm living a good life, I'm very content. […] Right now, I have to just be who I am, for as long as it takes. And that’s it. My purpose is to be still here as a mother or grandmother and try and be the best I can for as long as I can. And just be with my family. That’s it.’ [Page 15]

- **Living well on borrowed time: ‘*Of course, nobody knows, but 2010 was my expiry date, so I'm definitely living on borrowed time now’***

Name:	**Illustrative Extracts:**

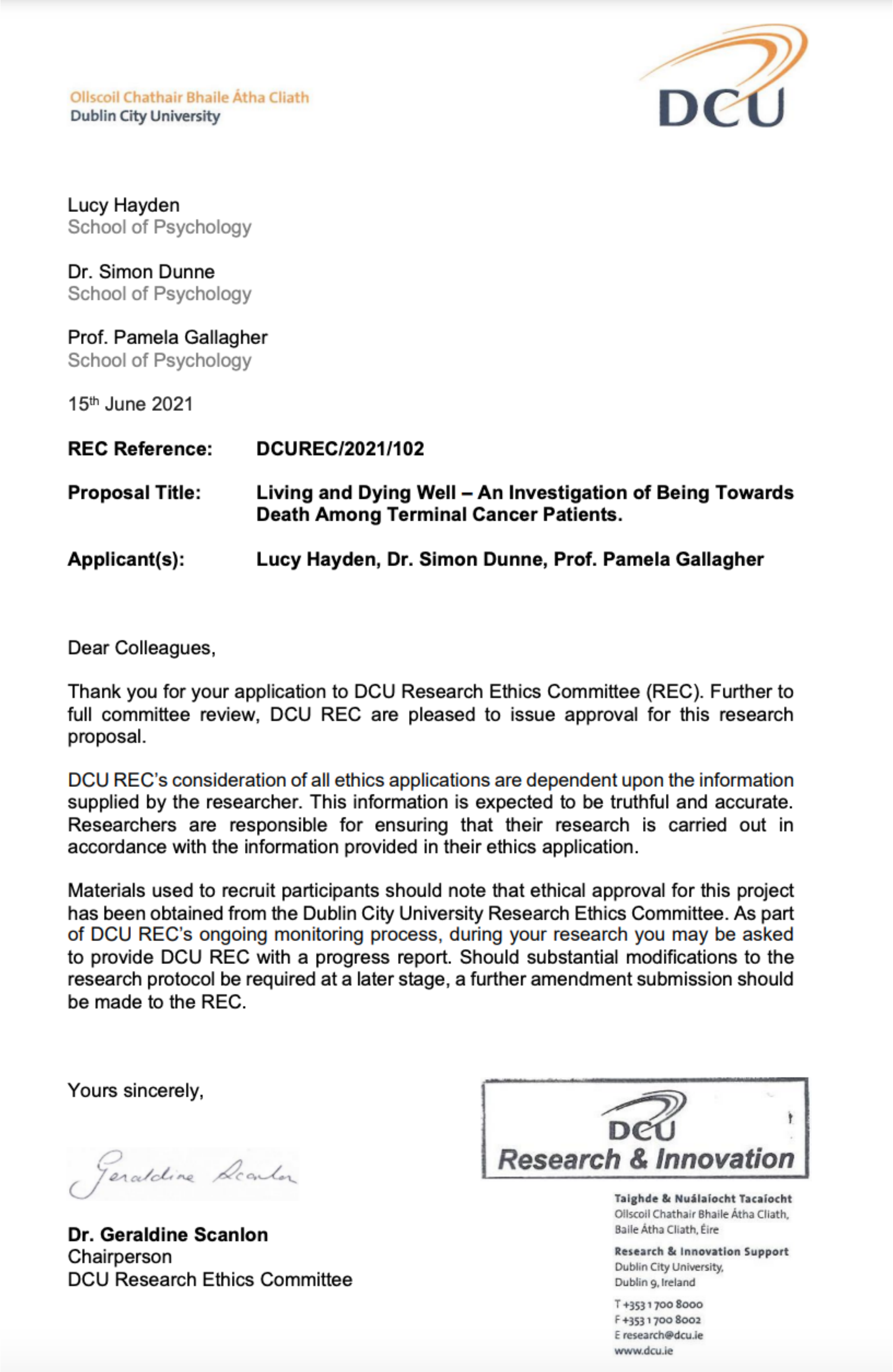
Ben / Appreciation of additional time	‘Every day I feel blessed when I wake up to continue on with life. I appreciate the time I have here, nothing is taken for granted. I suppose what I’m trying to say is I don’t take anything for granted anymore.’ [Page 4]
Danielle / Appreciation of time to enjoy life	‘You learn to appreciate life. […] You really get to appreciate your family and friends. […] It’s funny ‘cause I think we just live such busy, busy lives, we don’t take time to stop and smell the roses and appreciate it. […] I won't take them for granted again.’ [Page 14]
Joanne / Appreciation of time for growth	‘I suppose there was a learning in the whole journey. And like that, if it did anything, it made me stand back and you know, appreciate life and not take life for granted […] I live a much simpler life […] I don't have to be going out.’ [Page 30]
Layla / Appreciation of ‘borrowed’ time	‘Of course, nobody knows, but 2010 was my expiry date, so I'm definitely living on borrowed time now. So, I just have to keep living my life. […]I’m living a much fuller life. And I can thank cancer for that really.’ [Page 12]
Kiera / Additional time for growth	‘Initially I thought I’d be lucky if I got six months and then I was lucky I got a year and then it kind of started stretching out. […] [I’m] trying to learn more about myself and understand more about myself as I go along, […] now I think I'm more reflective. I've learned to be a bit more caring towards myself and value myself a bit more. […] My life has really changed now.’ [Page 14]

- **Leaving a legacy:** ***‘I'd like to be remembered as somebody who died well, having lived well’***

Name:	**Illustrative Extracts:**
Layla / Legacy of inspiration	‘I’d like to think that if they thought about me, they’d think about someone who says yes. […] I'd like to think that they can probably think of me and think, ‘oh well, she did that so I can do that. […] They can do whatever they want to do.’ [Page 15]
Joanne / Legacy of mother and friend	‘I suppose I've made a difference in the lives of people that I have known, and that I’ve been a good mother and a good friend, […] very approachable, and very hard working.’ [Page 26]
Diana / Legacy of parental role	‘I'd love to know what my children think of me. […] I'd like to think that they thought I did a good job. […] And funnily enough, my son […], he has given me so much praise of late about the life that he had, […] and it was such a joy to hear. So, I guess I've done something right.’ [Page 16]

Adele / Legacy of family & inspiring others	‘My legacy to begin with would be my two beautiful children, which has led to two lovely grandchildren. So that's a legacy in itself. I’d like to think that I am fondly remembered by people.’ [Page 17] ‘I’ve tried to get the word out there that you can be alive five years, ten years, fifteen years, twenty years after a diagnosis. So, I'd like that to be the legacy, you know, that you’re giving somebody strength somewhere.’ [Page 17]
Kiera / Legacy of family & fearlessness	‘My children really have turned out to be good citizens, they're good people, they’re my legacy. As well, not being afraid to try new things, […] ‘Feel the fear and do it anyway,’ that’s kind of my mantra.’ [Page 21]
Evelyn / Legacy of research	‘I joined the patient initiative programme. […] If I go tomorrow, I feel as if I’ve left a legacy that I've done something that might help my grandkids down the line. […] Hopefully, my little input […] will add to that light that I see for the future.’ [Page 5]
Ben / Legacy of helping others	‘I like the legacy that I help others with cancer now. Because I have such a positive outlook on it and attitude towards it, that my legacy is helping others with cancer. […] That helps me with my own.’ [Page 10]
Darragh / Legacy of benevolence	‘I like the concept of ‘do no harm’ a lot. So, I’d like to think that when people remember me, they will say ‘no, he didn't hurt anyone.’ […] I'd like to be remembered as somebody who died well, having lived well.’ [Page 37]

Appendix K - Ethical Approval Letter from DCU REC



Ollscoil Chathair Bhaile Átha Cliath
Dublin City University

DCU

Lucy Hayden
School of Psychology

Dr. Simon Dunne
School of Psychology

Prof. Pamela Gallagher
School of Psychology

15th June 2021

REC Reference:	**DCUREC/2021/102**
Proposal Title:	**Living and Dying Well – An Investigation of Being Towards Death Among Terminal Cancer Patients.**
Applicant(s):	**Lucy Hayden, Dr. Simon Dunne, Prof. Pamela Gallagher**

Dear Colleagues,

Thank you for your application to DCU Research Ethics Committee (REC). Further to full committee review, DCU REC are pleased to issue approval for this research proposal.

DCU REC's consideration of all ethics applications are dependent upon the information supplied by the researcher. This information is expected to be truthful and accurate. Researchers are responsible for ensuring that their research is carried out in accordance with the information provided in their ethics application.

Materials used to recruit participants should note that ethical approval for this project has been obtained from the Dublin City University Research Ethics Committee. As part of DCU REC's ongoing monitoring process, during your research you may be asked to provide DCU REC with a progress report. Should substantial modifications to the research protocol be required at a later stage, a further amendment submission should be made to the REC.

Yours sincerely,

Geraldine Scanlon

Dr. Geraldine Scanlon
Chairperson
DCU Research Ethics Committee

DCU
Research & Innovation

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Appendix L - Research Outputs and Dissemination Plan

Research outputs and dissemination plan

Title	Publication Medium	Output and Status	Related Chapter
A qualitative meta-synthesis examining spirituality as experienced by individuals living with terminal cancer.	*Health Psychology Open*	Manuscript, Published (Hayden et al., 2022).	Chapter 2
If you don't have hope, where is your future?: A qualitative study exploring the role of hope in the lives of those living with terminal cancer.	*Possibility Studies & Society* (proposed)	Manuscript, in preparation.	Chapter 5 and 6
Living and dying well: Exploring the role of connections and relationships within the terminal cancer experience	*Psycho-oncology* (proposed)	Manuscript, in preparation.	Chapter 5 and 6
Living on borrowed time: an interpretative phenomenological analysis of individuals' experiences living with terminal cancer.	*Journal of Cancer Survivorship* (proposed)	Manuscript, in preparation.	Chapter 5 and 6
A qualitative meta-synthesis examining spirituality as experienced by individuals living with terminal cancer.	*35th Annual Conference of the European Health Psychology Society* (online, due to COVID-19, August 2021).	Conference presentation (poster), presented.	Chapter 2
If you don't have hope, where is your future?: An interpretative phenomenological analysis of the	*3rd International Conference of Possibility Studies* (Dublin, July 2023).	Conference presentation (oral), presented.	Chapter 5 and 6

experience of living with terminal cancer.			
Living on borrowed time: an interpretative phenomenological analysis of individuals' experiences living with terminal cancer.	*Trinity Health and Education International Research Conference* (Dublin, March 2024)	Conference presentation, abstract submitted.	Chapter 5 and 6

PPI Engagement for Dissemination Purposes

Public and patient involvement (PPI) plays an integral role in cancer research. While undertaking this project, the researcher attended several PPI workshops held by DCU PPI Ignite, the Irish Cancer Society and Breakthrough Cancer Research. These workshops helped the researcher to gain an understanding of PPI in research, understand the benefit of PPI in research and to communicate my research effectively to those with a non-scientific background. PPI was invaluable to the researcher in learning how to communicate this research to a lay audience and learning how to translate research findings into information to help patients living with terminal cancer.

The researcher consistently engaged with PPI groups associated with Breakthrough Cancer Research during the time of their PhD. The researcher developed their skills in communicating and presenting this research through their attendance at research workshops held by Breakthrough Cancer Research focused on topics such as media communication among others. This involved meeting with representatives of Breakthrough Cancer Research's PPI group including patients, caregivers, and members of the public. During these workshops the researcher had the opportunity to have collaborative discussions with PPI representatives on how to communicate research findings in easily accessible language to a lay audience. The researcher worked together with individual patient representatives to translate the project summary into accessible language for media and collaborated on writing a blog post for social media to share the findings of this research. The researcher also obtained training in the creation and development of infographics to communicate my research in the media. Together with PPI representatives, the researcher created an infographic of these research findings suitable for a lay audience and shared this on the social media accounts created as part of the dissemination plan associated with this PhD.

Appendix M – Researcher Positioning and Reflexivity Statement

Researcher Positioning and Motivation for this PhD Study

My interest in the experience of terminal illness began almost thirty years ago when I was an undergraduate student in Trinity College Dublin. During the third year of my Sociology degree, I completed a module on the topic of 'Sociology of Health and Illness'. I had significant interest in this module as during the previous few years, some members of my wider family had died following a terminal cancer diagnosis in close succession to each other. Some of these family members had received end of life care in hospices, while others had died in acute hospitals. At the time, there were few hospices in Ireland and the perception of hospices among the general population was that they were a place where one went to die. During that time also, there were debates in the Netherlands regarding euthanasia, which spurred conversations in the Irish media about assisted dying. I decided to complete my dissertation in the field of terminal illness. I conducted a study titled 'The Choice of Care in the Event of Terminal Illness.' As part of this study, I interviewed family members who had previously cared for loved ones who had died from terminal disease. I was interested in exploring whether participants' experience of a loved one's death had an impact on how they might wish to be cared for, should they find themselves in a similar situation in the future. The findings suggested that participants whose loved ones had received palliative care in hospices experienced quality of life, dignity and peace in their final days of life. Despite their previous perceptions of hospices, each of these participants expressed a wish to avail of palliative care in a hospice setting, should they be diagnosed with terminal disease in the future. The findings also highlighted how participants whose loved ones had died in acute hospital settings had suffered emotionally and struggled with maintaining dignity in their final days. Several of these participants reported feeling emotional distress throughout this experience and did not wish for this type of care for themselves in the future.

Some years later, I found myself acting as an informal caregiver to a family member who had been diagnosed with terminal cancer. This family member attended an acute hospital for their care. It was noted by the oncology team that the type of terminal cancer which had been diagnosed might cause feelings of depression within this individual. As part of their care plan, this family member was subsequently prescribed anti-depressants. Despite receiving excellent care to support their physical disease, they received no psychological support to address their emotional and existential suffering. Since the death of this family member, other members of my wider family and friends have died from a similar diagnosis. They also spoke about the high quality of care they received to support their physical needs however, similar to my deceased loved one, they noted the lack of emotional support available to them.

In 2018, I returned to education and completed a master's degree in psychology. Based on my interest in terminal cancer and my experience in caregiving, I submitted a proposal to conduct a research project exploring the psychosocial and spiritual needs of terminal cancer patients. I interviewed caregivers who had previously cared for loved ones with terminal cancer. The findings of this study highlighted how participants' family members in many cases, had reported that medical professionals in acute hospital settings had not sufficiently addressed the psychosocial and spiritual needs of their family members. The findings further highlighted how these terminally ill individuals had experienced a lack of dignity and had struggled with mental health difficulties as they approached end of life. I submitted a manuscript of this study for publication to Omega Journal of Death and Dying and this article was published online in 2020.

Following on from my master's degree, I was very interested in researching this area of terminal cancer further and I submitted a proposal to complete a PhD in psychology. As part of this, I wished to explore the experience of living with terminal cancer, from the perspective of the patients themselves to further understand the phenomenon of 'living while dying'. As a part of this decision, I made an application to the Irish Research Council Enterprise Partnership Scheme (EPS) with Breakthrough Cancer Research and was awarded funding for this research. I felt that this partnership was appropriate given the Breakthrough aim to fund research on poor prognosis cancers (which would align with my focus on terminal cancer) and due to the additional learning opportunities that I could avail of due to the assignment of a research mentor as well as my own supervision team. I commenced my research in September 2019.

Anticipations and Expectations

Based on my own former experiences as an informal caregiver to family members living with terminal cancer, I had anticipated conducting this research in healthcare settings, where the participants would be inpatients of hospitals and hospices, or outpatients receiving medication for pain and symptom management. Based on prior projects I had worked on, I expected to find that participants had participants may report physical symptoms associated with living with their terminal disease, as well as potential psychological, social and spiritual distress. I was aware of these potential biases, and I managed these possible influences on my research through constant reflection and discussions with my supervision team from the beginning of the research process.

When I set out to conduct a study about the experiences of terminal cancer patients, I had intended to apply for ethical approval to gain access to collect data in clinical sites. I had envisaged interviewing participants who were in their final months of life, and I assumed that participants would be experiencing varying degrees of physical, emotional and/or spiritual distress. I had envisaged that these patients would appear how I perceived cancer patients to look, such as appearing physically unwell due to symptoms associated with their disease or following treatment, such as possible hair loss and perhaps hair regrowth. However, due to Covid 19 restrictions which began in March 2020, just six months after starting my PhD, it became clear that it was not possible to interview terminal cancer patients who were receiving inpatient care, as healthcare professionals in clinical sites were no longer able to support outside research during this time. Instead, I revised my recruitment strategy and contacted cancer centres, cancer charities and I used social media channels to recruit participants.

The only participant that I met in person was a female named ‘Layla’. We had arranged to meet in a hotel where she was staying. She was travelling to visit her family, whom she had not seen since before the start of the Covid 19 pandemic. As the travel restrictions had been recently lifted, she was able to see her family again, potentially for the last time. When I arrived at the hotel, I sent Layla a text message by phone, as we had previously agreed upon. I searched the lobby and somehow assumed that I might be able to identify her from the crowd who were scattered throughout. It was at this point, when I met her, that I began to recognise my own bias. I had assumed that this terminal cancer patient may possibly appear physically unwell, have potential hair loss and with possible translucent looking skin resulting from previous chemotherapy treatment. However, upon meeting Layla, I was struck by the fact that she had no outward signs of an individual who was living with terminal cancer. She did not appear physically unwell and had no apparent hair loss. As we walked together to find a seat, she appeared to walk slowly and carefully across the lobby. At this point, I began to recognise that the experience of living with terminal cancer was highly individualised, and that people can try to ‘live while dying’ to the best of their ability.

During the data collection and analysis phases of this study, there were many occasions when I reflected on my own previous experience of caring for loved ones living with terminal cancer, my previous training in alternative and holistic therapies and my own spiritual beliefs, and the potential biases that each of these may have brought to this research. I was cognizant of the possible influence that witnessing previous experiences of unmet care needs of other terminal cancer patients, specifically in terms of psychological and spiritual support, may have on my research. I was also aware of the possible influence of my own spiritual training and beliefs on the research. I managed these potential biases through constant reflection, identifying my own potential biases before commencing the research, journalling prior to and following each interview, discussion with my supervision team at each phase of the research and journalling my thoughts at the end of the research process.