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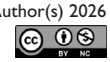
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'Life is all about hope': An interpretative phenomenological analysis of hope within the terminal cancer experience

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Abstract

A terminal cancer diagnosis is known to trigger psychosocial and existential concerns. Hope has been identified as a core need of patients at end-of-life; however limited research examines hope among individuals with terminal cancer specifically. This paper aimed to explore how hope was experienced, interpreted and sustained by individuals living with terminal cancer. Ten participants living with terminal cancer were recruited using purposive sampling. A cross-sectional research design was implemented with semi-structured interviews. Data was analysed using Interpretative Phenomenological Analysis. Two group experiential themes were generated from the data: *Living with Hope* and *Living in the Shadow of Hopelessness.* This paper highlights the complexity of hope in the context of terminal cancer. The findings suggest that hope theories should be broadened to encompass its diverse meanings across different contexts. These insights can guide the development of tailored interventions to support individuals as they navigate the terminal cancer experience.

Keywords

cancer, health psychology, interpretative phenomenological analysis (IPA), qualitative methods, illness

Introduction

Terminal cancer (TC) is defined as cancer that is not responsive to curative treatment and where one has a prognosis of less than 12 months (Cordeiro et al., 2020). Following a TC diagnosis, individuals may experience severe physical, psychosocial and spiritual distress due to the increased awareness of mortality (Adler and Page, 2008; Leung et al., 2006). Research suggests that individuals cope differently across the trajectory of incurable cancer, with strategies ranging from avoidant to active engagement depending on the individual (Bauer and Teply, 2023).

According to Snyder, hope refers to '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,

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1995: 355). Within this framework, hope comprises both cognitive and affective components and it is understood as a dynamic process involving agency and pathways thinking (Snyder, 2002). Agency thinking reflects beliefs about one's capacity to initiate movement towards goals (Corn et al., 2020), while pathways thinking involves generating routes to achieve them (Snyder, 1994, 2002). This model positions hope as a key psychological resource associated with resilience and goal attainment (Gallagher and Lopez, 2017).

Hope has also been identified as central to wellbeing and quality of life (QoL), particularly in contexts of adversity (Black et al., 2015). Positive future-oriented thinking may buffer against depression and anxiety, and hope is closely linked to meaning in life (Feldman and Snyder, 2005). Although TC may be perceived as a fundamentally hopeless situation, emerging literature suggests that hope remains a salient resource in coping with this experience (Hill et al., 2023). In this context, hope has been identified as integral to meaning-making and adaptation during adversity (McClement and Chochinov, 2008; Tugade et al., 2014). Importantly, experiences of hope are heterogenous, as while some TC patients maintain hope for a cure despite their prognosis (Chittem et al., 2022), others reorient hope towards QoL or a peaceful death without suffering (Eliott and Olver, 2009).

A small body of prior phenomenological research partially highlights hope in TC as a lived, interpretive, and meaning-laden experience rather than solely a measurable psychological construct. In the sole other phenomenological study examining hope in this context of which we are aware, Benzein et al. (2001) demonstrated that individuals with incurable cancer in a palliative care home navigate a dynamic tension between 'hoping for cure' and 'living in hope', reflecting an ongoing process of reconciliation with life and mortality. Extending this work, in their Interpretative Phenomenological Analysis (IPA) study, McTiernan and O'Connell (2015) found that individuals receiving palliative care often situate their illness within the continuity of their pre-illness identities, sustaining meaning through valued roles and everyday practices rather than through dramatic reappraisal. Together, these studies underscore the importance of exploring how hope is experienced and interpreted in the context of terminal illness.

In spite of these prior studies which reported on hope as part of a phenomenological enquiry into the TC experience, and other important findings on the role of hope and the meaning of hope in the context of TC (Baczewska et al., 2019; Daneault et al., 2016; Nierop-van Baalen et al., 2016; Sachs et al., 2013), there remains a lack of a purposeful in-depth qualitative exploration into how hope is subjectively experienced and sustained throughout the TC experience. As hope has been identified as a core need of patients at end-of-life (Bovero et al., 2021), levels of hope among cancer patients approaching death may vary (Ozen et al., 2020) and a dearth of research exists in the field of purposefully examining the experiences of hope among individuals with TC specifically. Given the salience of hope within the lives of those living with TC and the deeply personal nature of hope in this context, this paper seeks to address this gap by exploring how individuals living with TC experience, interpret and sustain hope in the context of their illness. The aforementioned phenomenological studies (Benzein et al., 2001; McTiernan and O'Connell, 2015) also underscore the potential importance of exploring how hope is experienced and interpreted in the context of terminal illness, thereby providing a clear rationale for adopting a phenomenological framework in the present study. In this context, this paper asks the following research question: *How is hope experienced, interpreted and sustained by individuals living with TC?*

Methodology

Research design

This paper formed part of a larger cross-sectional qualitative project exploring the

experience of living with TC and employed an interpretative phenomenological analysis (IPA) approach using semi-structured interviews (Smith et al., 2009, 2021). IPA was selected due to its focus on how individuals make sense of significant life experiences within their social and personal worlds (Smith and Nizza, 2022). IPA is particularly useful in the context of health research as it facilitates an in-depth exploration of how individuals experience and ascribe meaning to major life events such as illness (Smith, 2008; Smith et al., 2009).

Participants and recruitment

In line with IPA principles, a purposive sample of 10 individuals living with TC was recruited. Eligible participants were English-speaking adults ($\geqslant$18 years) with capacity to provide informed consent, a confirmed terminal cancer diagnosis and an oncologist-estimated prognosis of $\leqslant$12 months. All participants (including those initially diagnosed with metastatic disease) had been confirmed to have less than 12 months to live. At the time of interview none were receiving curative treatment, although palliative care for symptom management was permitted. Exclusion criteria included a prognosis $>$ 12 months or current curative treatment.

Participants were recruited through local and national cancer centres and cancer charities. Recruitment posters were distributed via support services, newsletters and social media platforms. Thirteen individuals who expressed interest were deemed ineligible due to either not meeting the prognosis criteria or being in receipt of curative treatment.

Data collection

This research received ethical approval from the institutional review board of the researchers' host institution (Approval Number: DCUREC/2021/102). As part of this paper, participants were asked about their perception of the meaning of hope and the hope within their experience of living with TC. This was part of an open-ended phenomenological interview centring on four central questions (*Can you tell me about what it's like to live with cancer that can't be cured? What aspects of your life are most important to you? What gives you meaning and purpose in life? How do you wish to live for the rest of your life?*) which allowed space for participants to explore important issues and meanings for them. Due to the central importance of the topic of hope in this context, this included asking participants specific questions such as 'tell me about hope in your life' and 'what does hope mean to you?'

Recruitment proceeded with participants making initial contact with the first researcher by email and providing contact details for this researcher to reply to them by phone. During this contact, the researcher confirmed that participants satisfied the inclusion criteria, provided information about the research, established a rapport with participants and answered any questions participants had about the study. Following this, the researcher agreed the location of the interview with participants. Due to the vulnerable health status of most participants, one interview was conducted in-person, and nine interviews were conducted remotely. Prior to each interview, participants were sent an information sheet and a consent form and were requested to return a signed copy of the form to the researcher, indicating their consent to take part in the study. A risk management protocol for conducting online interviews was also designed by the first researcher to protect the participants' and researcher's wellbeing during the data collection process. Interviews were audio-recorded and transcribed verbatim.

Data analysis

Following transcription, the first researcher removed all identifiable information including names, locations and hospitals from the data to ensure anonymity and confidentiality for all participants. The data was then analysed on a case-by-case basis in line with the IPA method (Smith et al., 2021). The steps of this process included firstly reading and re-reading the transcript to immerse oneself in the data and to gain

familiarity of the lifeworld of the participant. The second step involved making initial exploratory notes of the content. These notes were either linguistic, descriptive or conceptual in nature. The third step involved the construction of experiential statements. The fourth step involved identifying connections across experiential statements. The fifth step involved naming personal experiential themes (PETs). The sixth step involved repeating the process across other cases. The final step involved exploring convergences and divergences in the data to construct group experiential themes (GETs) across the cases. Data analysis was discussed and checked by the second and third researchers at each step of the analytic process. Two GETs relating to the aim of this paper were identified from this data (Smith and Nizza, 2022).

Research team and reflexivity

Reflexivity was conceptualised as an ongoing, critical engagement with the researcher's interpretative role rather than solely as the identification of bias (Finlay, 2002). In line with IPA's 'double hermeneutic', the researcher is engaged in making sense of participants' meaning-making processes (Smith et al., 2021). The research team comprised three researchers (two female, one male) who had several years' experience in conducting qualitative research with cancer patients and their caregivers. The first researcher, who conducted all interviews and led the analysis and writing of the final report, had prior personal experience of caring for a family member with TC. This positionality was explicitly acknowledged and discussed within the team prior to data collection, recognising that such experience may both sensitise and shape interpretative engagement (Berger, 2015). Reflexivity was enacted through pre-interview reflection, post-interview field notes and team debriefings and ongoing analytic journalling during theme development. These processes enabled continuous critical examination of how assumptions, emotional responses and experiential knowledge informed interpretative decisions, thereby enhancing transparency and analytic rigour.

Results

Ten individuals with TC participated, consisting of eight females and two males. The average age of participants was 57.3 years with a range of 42–80 years old. Eight participants were of Irish heritage, while two participants were of British descent, and both had lived in Ireland for over two decades. Interviews ranged from 50 to 109 minutes (with a mean interview length of 76 minutes). Further participant demographic information is provided in Table 1.

Two group experiential themes (GETs) relating to the experience, interpretation and sustainability of hope by individuals living with TC were developed from the data by the researchers. Each of the GETs and subthemes are presented in Table 2.

Theme 1: Living with Hope: 'If you don't have hope, where is your future?'

Despite their awareness of a limited prognosis, participants described hope as central to how they engaged with life. Hope was experienced by participants as an abstract belief, a motivating force and an orientation towards future possibilities. Across accounts, hope was not static but actively sustained and reworked in response to changing circumstances. In this way, hope functioned as a dynamic resource that enabled participants to navigate uncertainty, maintain engagement with daily life, and orient themselves towards what remained possible.

Holding onto hope: Hope as an abstract belief. Several participants described hope as a belief which enabled them to persevere through difficulty and look towards the future with optimism. In several cases, hope played a central role in enabling them to live in a meaningful and positive way, despite their prognosis. For instance, one participant described:

Table 1. Participant characteristics.

Name	Age	Gender	Primary Cancer Type	Time since initial diagnosis	Type of initial diagnosis	Time since terminal diagnosis	Marital status
Layla	42	Female	Ovarian	13 years	Metastatic	10 years	Single
Evelyn	60	Female	Breast	17 years	Metastatic	5 years	Separated
Kiera	50	Female	Multiple Melanoma	16 years	Metastatic	6 years	Married
Danielle	56	Female	Colon	5 years	Metastatic	1 year	Single
Diana	80	Female	Bowel	3 years	Terminal	3 years	Widowed
Adele	58	Female	Breast	5 years	Terminal	5 years	Married
Joanne	59	Female	Lymphoma	7 years	Metastatic	4 years	Separated
Ben	46	Male	Colorectal	11 years	Metastatic	2 years	Separated
Darragh	58	Male	Sarcoma	15 years	Metastatic	1.5 years	Married
Linda	64	Female	Breast	6 months	Terminal	6 months	Separated

Table 2. Group experiential themes and subthemes.

Group experiential themes	Subthemes
Living with Hope: *'If you don't have hope, where is your future?'*	*Holding onto Hope*: Hope as an Abstract Belief
	Drawing Strength from Hope: Hope as a Motivating Force
	Looking Ahead with Hope: Hope as an Appreciation of Future Possibilities
Living in the Shadow of Hopelessness: '*There is no hope, is there?'*	*Grieving a Lost Future*: Hopelessness as Loss of Future Possibilities
	Confronting Mortality: Hopelessness as Existential Despair
	Reaching the Edge of Endurance: Hopelessness as Insurmountable Challenges

> *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)

This illustrates how, despite awareness of reduced life expectancy, hope enabled participants to orient towards the future while living with uncertainty, fostering emotional stability in times of challenge. Related to this, participants highlighted how hopeful beliefs can support positive expectations towards the future:

> *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. [. . .] 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.* (Diane)

The use of evocative language and vivid metaphors in this example demonstrate the power of hope as a means of looking beyond challenges and difficulties when living with terminal cancer. The metaphors of light and candles suggest that hope can illuminate the darkness during times of difficulty and despair. 'Somebody else will shine it' indicates the relational aspect of hope and 'it's there for all' suggests the universality of the hope experience. For many participants in this way, hope was not dependent upon an expected outcome in the future, but was an inner belief system which helped them to relate to their future and to others and to live with emotional balance while navigating the uncertainty of their prognosis. Similarly, another participant reflected on how hope helped him to look beyond current challenges:

> *Hope, I am a great believer in hope. I am actually a huge believer in hope. [. . .] 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)

This quote further illustrates how hope can facilitate individuals with TC to look beyond present challenges and maintain a future-oriented outlook future despite uncertainty.

This subtheme demonstrates that, for many participants, hope was experienced as a sustaining belief. Notably, this belief was not connected with hope for a cure or for certainty, but rather as a mindset which helped them to live with meaning. In this way, hope functioned as an emotional anchor, allowing participants to remain oriented towards the future despite their terminal condition.

Drawing strength from hope: Hope as a motivating force. For most participants, hope was not merely an abstract belief but functioned as a practical and motivating resource. Participants described how hope supported them in navigating times of challenge and struggle. For instance, one participant described how she actively cultivated hope to help herself to live with TC:

> *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.' [. . .] 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. [. . .]. I mean I was down to my last few weeks and that's a lot to think about.* (Kiera)

This quote highlights the intentional and effortful nature of hope, which many participants actively fostered to sustain themselves through difficult periods. In this way, hope enabled participants to focus on milestones and persevere through adversity. Similarly, another participant described structuring her day through small goals:

> *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 just kept building from there over time.* (Evelyn)

By setting small manageable goals, Evelyn and other participants created structure and sustained motivation, enabling them to persevere through present challenges. In doing so, they were able to move through periods of difficulty while maintaining a sense of progress and an orientation towards better times ahead. Extending this, participants also described hope as a primary motivating force that sustained their engagement with life in the context of their diagnosis:

> *[Hope is] what's keeping me going. Optimism, hope, yes, hope is a big thing, yeah that would be the primary motivation. Instinct for survival, hope and optimism, whilst being realistic about my situation. [. . .] None of these emotions or feelings stand alone, 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)

In line with this example, many participants equated hope with optimism, a central emotional motivating force that helped to support and sustain their wellbeing. 'None of these feelings stand alone' suggests that hope is a key facet of an integrated system, comprising optimism, belief, trust and realism. In this way, for many participants, hope co-existed with the knowledge of a shortened life expectancy, yet empowered participants to make the most of their lives.

Across many participants, hope manifested as a motivational force which participants constructed for themselves as a means of navigating their way through times of challenge. Whether through setting short term goals, focusing on milestones or taking an integrative perspective, hope was an inner resource used by participants to empower themselves to survive and life live more fully, despite the awareness of their prognosis.

Looking ahead with hope: Hope as an appreciation of future possibilities. Participants also described living with hope as an appreciation of the possibilities that might still lie ahead for them, such as the possibility of maintaining QoL, having a peaceful death and life beyond death. Participants spoke about hope as a means of contemplating a future that was limited, yet still worthy of possibility. When challenged with TC, hope provided emotional nourishment and spiritual peace, helping participants to live with meaning and optimism. For instance, one participant spoke about hope for continued QoL and the possibility of them experiencing joy in the future:

> *I hope that I'll live for as long as possible and hope that I'll have a good QoL. That I'll continue to enjoy life. Hope that I will maintain this attitude and that nothing will happen to change it.* (Danielle)

This quote demonstrates how, for many participants, hope supported positive expectation for the future and sustained engagement with life. Imagining future enjoyment and the possibility of good QoL enabled participants to live their lives with optimism.

As participants reflected upon the prospect of end-of-life, many also spoke about hope as a means of continuing to live with dignity and peace while dying, and the possibility of having a peaceful death:

> *I would like to think that I'm somewhere comfortable, be it at home or be it in a hospice, somewhere comfortable. And I'm being taken care of as best I can and I'm in no pain. That's what I would hope for. [. . .] I would like to think my final days would be peaceful and restful and that I'd leave the world in a way that is not upsetting for my family. That they have a nice memory of my passing.* (Adele)

> *I'd like to die peacefully, hopefully, without being in pain.* (Darragh)

These quotes demonstrate the consistent finding among participants that hope was oriented towards the possibility of comfort, QoL in their final days and a peaceful death, including being cared for and free from pain. In this way, hope extended beyond survival to encompass dignity and relational concerns for both them and their families.

Other participants spoke about the emotional role that hope played in their lives while living with their disease:

> *I suppose if you didn't have hope, you'd have nothing. You always hope for something, don't you? Something nice and something good. Without hope, life would be very dull. [. . .] Hope is a good thing for people, I wouldn't live my life without hope.* (Ben)

For participants like Ben, hope was closely linked to emotional wellbeing and shaped how they engaged with life as an appreciation of future possibilities. Rather than focusing on their prognosis, several participants maintained an optimistic outlook and a belief in the potential for positive daily experiences, with hope sustaining a sense of meaning and possibility.

In contrast, other participants spoke about balancing hope with realism as they looked towards the future:

> 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)

Layla's account highlights a dynamic balance between hope for the future and a realistic appraisal of what remains possible, alongside an acceptance of the limitations of living with a

life-limiting condition. Rather than abandoning hope following their diagnosis or living in denial, several participants intentionally created space for possibility in their lives grounded in the realism of their situation in this way.

Across multiple accounts, participants shared their appreciation for the future as meaningful possibilities, such as maintaining QoL, a peaceful death and life beyond death. In these ways, hope represented an orientation towards possibilities that still exist in the face TC.

Theme 2: Living in the shadow of hopelessness: 'There is no hope, is there?

Alongside hope, participants described periods of hopelessness that emerged in response to the realities of living with TC. As they confronted the implications of their diagnosis, many recalled moments in which hope began to slip away. While not always entirely absent, feelings of hopelessness cast a shadow over their day-to-day lives and influenced how they engaged with their illness. In this way, living in the shadow of hopelessness reflected a fragile and fluctuating relationship with hope, shaped by the ongoing uncertainty of the disease rather than its complete loss.

Grieving a lost future: Hopelessness as loss of future possibilities. As participants lived with the reality of their terminal condition, several spoke about their struggle with continued periods of hopelessness associated with the recognition that their previously desired or imagined futures were no longer attainable. For instance, one participant described her feelings of hopelessness since receiving her diagnosis:

> *There is no hope, is there? [. . .] 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)

This account reveals how being given a short prognosis can result in a loss of perceived ability to live with hope and optimism for the future. This sense of hopelessness in future possibilities can lead to a lack of satisfaction in daily activities and apathy towards engaging in healthy behaviours. The allusion of the 'Sword of Damocles' hanging over one's head conveys a persistent awareness of threat that disrupts the enjoyment of life and anticipation of future possibilities. The use of words such as 'meaningless' and 'pointless' point towards participants' disconnection from finding meaning in the future. Other participants' accounts of feeling hopeless for future possibilities were experienced as a loss of purpose, for example, through involuntary retirement and loss of corresponding professional identity. As one participant explained:

> *But then my life changed because I was told I wasn't allowed to work in construction anymore. [. . .] So, I was put straight away on 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. [. . .] Now, I'm not doing anything, and it does play on me.* (Ben)

This account highlights how a shift in identity from being a person in the world in active employment to no longer having the possibility of ever being allowed to work again can cause an individual with TC significant emotional distress. The use of emphatic language such as 'kills me' and 'scared sick' highlights the profound impact that loss of purpose and identity can have on an individual's self-concept, particularly in relation to independence and employment. This lack of daily purpose alongside

increased dependence on income support, contributed to several participants' sense of hopelessness regarding future possibilities.

In this way, for several participants, hopelessness was experienced as an emotionally distressing disconnection from imagined futures, roles, and source of meaning.

Confronting mortality: Hopelessness as existential despair. Participants reflected on moments of profound hopelessness following their TC diagnosis. This overwhelming feeling of hopelessness extended beyond their prognosis to existential dimensions of meaning and connection in their lives. Several participants described how they lived with a greater sense of uncertainty about the future than before and perceived the imminence of death, which challenged their previous assumptions about the longevity of their lives. The hope which participants once attached to long term goals and imagined futures became distant and unattainable. One participant recounted an isolating moment following her TC diagnosis in this vein:

> *I just thought I was on my own, the only person out 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)

Confronting the unavoidable reality of one's mortality in this way led many participants to experience moments of existential despair, isolation and hopelessness for the future. In these moments, participants experienced a deep sense of loneliness and isolation due to an inability to find others who had received a similar diagnosis, and thereby locate themselves within a community of shared experience. These participants experienced a sense of existential despair, suffering over the uncertainty of their life expectancy and felt hopeless for the possibility of having a future.

Similarly, several other participants struggled with living in the shadow of TC. One participant articulated her feelings of existential despair even on seemingly joyful occasions:

> *There was a lot of stuff that was very emotional, even on Mother's Day, we went out for a meal. On my birthday, I had a complete meltdown on my birthday, much to everyone's surprise. But I was convinced it was my last birthday but they were all like, 'you know, you can't think that it's your last birthday.' [. . .] And I was like, 'I know how sick I am.' [. . .] I was afraid of falling apart and [. . .] I was like 'if you only had any idea how hard it is to keep going.* (Kiera)

This account reveals a conflict between the internal turmoil experienced by the individual with TC and the external world around them. The knowledge of their finitude affects the individual with TC's ability to experience everyday events like a birthday or Mother's Day and causes significant emotional distress, perceiving it may potentially be their last one. The fear of 'falling apart' and difficulties 'to keep going' reveal the emotional exhaustion experienced by an individual with TC in sustaining hope in the face of their prognosis.

These participant accounts reveal how hopelessness is often experienced as profound existential despair by the individual with TC in terms of how they related to life, their future and their social world.

Reaching the edge of endurance: Hopelessness as insurmountable challenges. Several participants described periods in which the physical and emotional challenges of living with their illness became overwhelming and difficult to endure. During these times of intense suffering and exhaustion, participants struggled to cope with what were experienced as insurmountable demands. One participant recalled moments of profound hopelessness while living with TC:

> *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 several participants like Evelyn, living through periods of physical challenge and emotional exhaustion became so overwhelming that they felt unable to continue with the struggle of living. The metaphor 'throwing in the towel' reveals these deep-seated feelings of defeat by circumstances. The accompanying wish not to 'wake up in the morning' signals the individual with TC's desire to surrender to their illness and the expression 'I'm done' reflects how the individual with TC may often wish to be relieved of the suffering they endure.

Several other participants spoke about how hopeless they felt during times of challenge:

> *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 several participants, hopelessness accumulated gradually over a sustained period in this way, due to effects of treatment and the presence of physical symptoms which became increasingly difficult to live with. The continued physical and emotional struggle to live with TC could become so immense that the individual 'just didn't want to do it anymore'. The expression that 'it was just too hard' reflects lost hope in one's ability to move beyond these challenges and struggling with sustaining the will to survive. In this way, for some participants, hopelessness was experienced as an inability to move beyond suffering during times of intense and sustained challenge and where the future felt inaccessible.

Across accounts, hopelessness was experienced as an inability to move beyond suffering during periods of intense challenge, where the future felt inaccessible and the effort of continuing became too great.

In summary, participants' accounts reveal a dynamic and fluctuating relationship between hope and hopelessness within the TC experience. Hope functioned as a sustaining, motivating and future-oriented resource, while hopelessness reflected moments of loss, existential distress and overwhelming challenge. Together, these findings highlight the non-linear and deeply personal nature of hope as lived within the context of terminal illness.

Discussion

To our knowledge, this is the first paper to offer an in-depth exploration of how hope is experienced, interpreted and sustained by TC patients specifically (outside of Benzein et al.'s (2001) research with individuals with incurable cancer in a palliative care home). While former studies have recognised the significance of hope at end-of-life (Beng et al., 2022; Laranjeira et al., 2022; Sachs et al., 2013), the findings of this paper suggest that hope is not experienced as a distinct or isolated construct, but rather as an embedded and dynamic aspect of the lived experience of TC, shaped by relational, emotional and existential dimensions. Across accounts, participants described a fluctuating relationships between hope and hopelessness, reflecting a non-linear process of adaptation to the realities of terminal illness.

The first GET, *Living with Hope*, highlights how participants engaged with hope as a vital, intentional and dynamic process through which they navigated the uncertainty of their poor prognosis, whether as an abstract belief, a motivating force or an orientation towards future possibilities. These findings extend current knowledge of how individuals with TC actively reshape hope to maintain emotional stability. Together, they illustrate that hope remained central to participants' experiences, not as a denial of finitude, but as a flexible and realistic resource that enabled them to live meaningfully while dying.

Several participants experienced *hope as an abstract belief* rather than solely as a goal-directed construct. Even in the absence of specific expectations, participants referred to hope as a fundamental mindset that was a foundation for their wellbeing. For TC patients, hope was something they clung to during difficult times, and became a vital component of their life outlook when navigating the TC experience. These

findings extend theories of hope such as Snyder's that suggests that hope is 'the perception that one can reach desired goals' (Snyder and Lopez, 2001: 257) by highlighting that hope may extend beyond goals and function as a stabilising psychological resource, supporting emotional equilibrium in the face of uncertainty.

As part of this GET, participants also described *hope as a motivating factor* within their lives that shaped their days, assisted them in organising and planning their life and sustained their emotional drive. This finding builds upon Snyder's theory of hope (Snyder, 1995, 2002), which highlighted that individual agency and goal-setting are key aspects of hope. Our findings in this context suggest that one's goals may be adapted during the TC experience as individuals move from a wish for survival towards seeking a good QoL as they approach end-of-life. While former studies across decades have highlighted that hope may act as a psychological buffer in the face of negative life events in different contexts (Bunston et al., 1995; Madan and Pakenham, 2014; Valle et al., 2006), this paper builds upon these findings by illustrating how hope may function not only as a cognitive process but as a lived, embodied practice that supports individuals in navigating the demands of living with TC.

As the final aspect of this GET, several participants viewed *hope as an appreciation of future possibilities* including QoL, relationships and a peaceful death. This shift away from cure reflects adaptive meaning-making, involving a dynamic negotiation between possibility and acceptance. Hope coexisted with realism, allowing openness to the future while recognising its constraints. These findings question assumptions that hope at end-of-life is necessarily unrealistic or cure-focused (Eliott and Olver, 2009), instead highlighting its flexible and context-sensitive nature.

The second GET, *Living in the Shadow of Hopelessness*, captures the fragility of hope and the ways in which it may be disrupted, suspended or momentarily lost. Participants' experiences of hopelessness were not indicative of the absence of hope, but rather reflected a fluctuating and often precarious relationship with it. This reinforces the conceptualisation of hope as a dynamic process that evolves in response to changing circumstances, rather than a stable psychological state.

In the first instance, participants perceived *hopelessness as loss of future possibilities*, characterised by a rupture in imagined life trajectories, roles and identities. The grieving of previously imagined futures highlights the extent to which hope is intertwined with an individual's sense of self and orientation towards the future. In this context, hopelessness reflects not only the loss of specific goals, but a broader disruption to meaning and identity. While previous research has suggested that patients' hopes may change over the course of illness, (Eliott and Olver, 2009), the present findings extend this by illustrating the emotional and existential impact of losing those possibilities.

Others experienced *hopelessness as existential despair*, particularly in moments when they confronted their mortality, uncertainty and isolation. These experiences were characterised by a disruption to participants' sense of continuity, belonging and emotional stability, echoing previous findings on existential distress at end-of-life (Morita et al., 2004; Ruijs et al., 2013). Importantly, these accounts highlight how awareness of one's finitude permeates everyday life, reshaping how individuals relate to ordinary experiences and life events.

Finally in relation to this second GET, participants viewed *hopelessness as insurmountable challenges*, where physical and emotional suffering became overwhelming and difficult to sustain. In these moments, hopelessness was experienced as an inability to continue coping, reflecting the cumulative impact of illness-related challenges. This finding extends existing literature that has primarily conceptualised hope as a marker of resilience (Park and Chen, 2016; Solano et al., 2016), by demonstrating that for some individuals, suffering may exceed their perceived capacity to cope. In this sense, hopelessness represents not a failure of coping, but a response to the profound demands of living with TC.

Taken together, these findings highlight the dynamic interplay between hope and hopelessness, suggesting that individuals living with TC move fluidly between these states, rather than progressing along a linear trajectory. Hope emerges as a relational, emotional and existential process that is continually negotiated in response to changing circumstances. This perspective adds nuance to existing understandings of hope by situating it within the lived complexity of terminal illness.

Strengths and limitations

There are several strengths and limitations to this paper which must be acknowledged. To our knowledge, this the first paper to conduct an in-depth exploration of hope specifically in the context of TC. Utilising IPA, we gained a unique and rich insight into hope within the TC experience, which would not have been possible using a quantitative methodology. A limitation of this paper was that the IPA method involves a small homogenous sample size and, therefore, the findings cannot be generalised among a wider population. Nonetheless, the rich experiential data collected captures the nuances of how hope was experienced, interpreted and sustained by individuals as they navigate living with TC.

Implications for future theory, research and practice

The findings of this research highlight several important directions for future theoretical development. Our findings suggest that, in the context of TC, existing hope theories may need to be extended to accommodate the diverse meanings of hope that individuals may hold in such contexts. These findings indicate that hope is dynamic in nature and may change across the trajectory of the TC experience. Future research could further investigate the dynamic interplay between hope and hopelessness within the illness experience. Our findings suggest that individuals do not follow a linear trajectory of hope, but instead oscillate between moments of despair and renewed hope. Longitudinal qualitative studies could explore how hope evolves over time in relation to changes in one's personal goals, symptom burden and illness progression.

In terms of practice, these findings highlight that hope is dynamic and is not universally defined. For some, hope may focus on cure, while for others it may shift towards finding peace, comfort or meaningful connection with others. This finding suggests that it may be useful for healthcare practitioners to explore what hope means for patients, rather than assuming it is static and predictable across the cancer trajectory. Attending to patients' narratives of hope may enable clinicians to better align care with what matters most to the person; whether this involves sustaining valued roles, achieving short-term goals, maintaining relationships or preserving dignity. Clinically, this highlights the importance of exploring what patients are hoping for at different stages of illness, enabling more person-centred communication, alignment of care with individual values, and sensitive support of psychological and existential well-being. Further, as this paper identified that hope served as a motivating force or emotional anchor for individuals, care plans should reflect what patients are hopeful of; whether that is symptom control, meaningful connection or reaching personal goals. Additionally, the findings highlight hope is shaped by emotional, existential and relational factors. Multidisciplinary teams, including medical and allied-health professionals, can play a role in supporting patients to navigate their experiences of hope and hopelessness. Integrating these supports can ensure that these dimensions are addressed holistically for patients.

Conclusion

This paper explored how individuals living with TC experience, interpret and sustain hope. Hope emerged as a dynamic, multifaceted and deeply embedded aspect of the TC experience, in some moments functioning as an emotional anchor, a

motivating resource and an orientation towards meaningful possibilities. At the same time, participants experienced moments of hopelessness characterised by loss, existential distress and overwhelming challenge. These findings highlight the interplay between hope and hopelessness within the TC experience. By conceptualising hope both as a coping resource and a meaningful existential response, this paper extends current understandings of hope at end-of-life. Supporting patients in ways that acknowledge both the presence and fragility of hope may enhance compassionate and holistic care.

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Ethical considerations

This research was completed in line with the Declaration of Helsinki and was approved by the research ethics committee of Dublin City University (Approval Number: DCUREC/2021/102).

Consent to participate

Informed consent was obtained from all individual participants included in the study.

Consent to publication

Informed consent regarding the potential publication of pseudonymized data in an academic journal or conference was obtained from participations prior to participation in this research.

Author contributions

Lucy Hayden: Conceptualisation, data curation and design, data analysis and interpretation, original manuscript preparation, writing, review and editing, funding acquisition. Pamela Gallagher & Simon Dunne: Conceptualisation, supervision, interpretation, manuscript review and editing.

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Data availability statement

The datasets generated and/or analysed during this study are available from the corresponding author on reasonable request.*

References

Adler NE and Page AE (2008) *The Psychosocial Needs of Cancer Patients, Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*. National Academies Press (US).

Baczewska B, Block B, Kropornicka B, et al. (2019) Hope in hospitalized patients with terminal cancer. *International Journal of Environmental Research and Public Health* 16: 3867.

Bauer A and Teply M (2023) How patients cope throughout the course of an incurable cancer. *Clinical Colorectal Cancer* 22: 347–353.

Beng TS, Xin CA, Ying YK, et al. (2022) Hope in palliative care: A thematic analysis. *Journal of Palliative Care* 37: 177–182.

Benzein E, Norberg A and Saveman BI (2001) The meaning of the lived experience of hope in patients with cancer in palliative home care. *Palliative Medicine* 15(2): 117–126.

Berger R (2015) Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative Research* 15(2): 219–234.

Black BP, Wright PM and Limbo R (2015) *Perinatal and Pediatric Bereavement in Nursing and Other Health Professions*. Springer Publishing Company.

Bovero A, Opezzo M, Botto R, et al. (2021) Hope in end-of-life cancer patients: A cross-sectional analysis. *Palliative & Supportive Care* 19: 563–569.

Bunston T, Mings D, Mackie A, et al. (1995) Facilitating hopefulness: The determinants of hope. *Journal of Psychosocial Oncology* 13: 79–103.

Chittem M, Eliott J and Olver I (2022) Demonstrating the importance of cultural considerations at end of life utilizing the perspective of Indian patients with cancer. *Supportive Care in Cancer* 30: 2515–2525.

Cordeiro FRG, Oliveira SG, Giudice JZ, et al. (2020) Definitions for "palliative care", "end-of-life" and "terminally ill" in oncology: A scoping review. *Enfermería: Cuidados Humanizados* 9: 205–228.

Corn BW, Feldman DB and Wexler I (2020) The science of hope. *Lancet Oncology* 21: e452–e459.

Daneault S, Lussier V, Mongeau S, et al. (2016) Ultimate journey of the terminally ill: Ways and pathways of hope. *Canadian Family Physician Medecin de Famille Canadien* 62: 648–656.

Eliott JA and Olver IN (2009) Hope, life, and death: A qualitative analysis of dying cancer patients' talk about hope. *Death Studies* 33: 609–638.

Feldman DB and Snyder CR (2005) Hope and the meaningful life: Theoretical and empirical associations between goal–directed thinking and life meaning. *Journal of Social and Clinical Psychology* 24: 401–421.

Finlay L (2002) Negotiating the swamp: The opportunity and challenge of reflexivity in research practice. *Qualitative Research* 2(2): 209–230.

Gallagher MW and Lopez SJ (2017) *The Oxford Handbook of Hope*. Oxford University Press.

Hill DL, Boyden JY and Feudtner C (2023) Hope in the context of life-threatening illness and the end of life. *Current Opinion in Psychology* 49: 101513.

Laranjeira C, Dixe MA, Semeão I, et al. (2022) "Keeping the light on": A qualitative study on hope perceptions at the end of life in Portuguese family dyads. *International Journal of Environmental Research and Public Health* 19: 1561.

Leung KK, Chiu TY and Chen CY (2006) The influence of awareness of terminal condition on spiritual well-being in terminal cancer patients. *Journal of Pain and Symptom Management* 31: 449–456.

Madan S and Pakenham KI (2014) The stress-buffering effects of hope on adjustment to multiple sclerosis. *International Journal of Behavioral Medicine* 21: 877–890.

McClement SE and Chochinov HM (2008) Hope in advanced cancer patients. *European Journal of Cancer* 44: 1169–1174.

McTiernan K and O'Connell M (2015) An interpretative phenomenological analysis exploring the lived experience of individuals dying from terminal cancer in Ireland. *Palliative & Supportive Care* 13(3): 641–651.

Morita T, Kawa M, Honke Y, et al. (2004) Existential concerns of terminally ill cancer patients receiving specialized palliative care in Japan. *Supportive Care in Cancer* 12: 137–140.

Nierop-van Baalen C, Grypdonck M, van Hecke A, et al. (2016) Hope dies last . . . A qualitative study into the meaning of hope for people with cancer in the palliative phase. *European Journal of Cancer Care* 25: 570–579. https://doi.org/10.1111/ecc.12500

Ozen B, Ceyhan O and Büyükcelik A (2020) Hope and perspective on death in patients with cancer. *Death Studies* 44: 412–418.

Park J and Chen RK (2016) Positive psychology and hope as means to recovery from mental illness. *Journal of Applied Rehabilitation Counseling* 47: 34–42.

Ruijs CD, Kerkhof AJ, van der Wal G, et al. (2013) Symptoms, unbearability and the nature of suffering in terminal cancer patients dying at home: A prospective primary care study. *BMC Family Practice* 14: 201.

Sachs E, Kolva E, Pessin H, et al. (2013) On sinking and swimming: The dialectic of hope, hopelessness, and acceptance in terminal cancer. *American Journal of Hospice and Palliative Medicine* 30: 121–127.

Smith JA (ed.) (2008) *Qualitative Psychology: A Practical Guide to Research Methods*, 2nd edn. Sage Publications.

Smith JA, Flowers P and Larkin M (2009) *Interpretative Phenomenological Analysis: Theory, Method and Research*. Sage.

Smith JA, Flowers P and Larkin M (eds) (2021) *Interpretative Phenomenological Analysis: Theory, Method and Research*, 2nd edn. Sage Publications Ltd.

Smith JA and Nizza IE (2022) *Essentials of Interpretative Phenomenological Analysis*. American Psychological Association.

Snyder CR (1994) *The Psychology of Hope: You Can Get There From Here*. Simon and Schuster.

Snyder CR (1995) Conceptualizing, measuring, and nurturing hope. *Journal of Counseling & Development* 73: 355–360.

Snyder CR (2002) Hope Theory: Rainbows in the Mind. *Psychological Inquiry* 13: 249–275.

Snyder CR and Lopez SJ (2001) *Handbook of Positive Psychology*. Oxford University Press.

Solano JP, da Silva AG, Soares IA, et al. (2016) Resilience and hope during advanced disease: A pilot study with metastatic colorectal cancer patients. *BMC Palliative Care* 15: 70.

Tugade MM, Shiota MN and Kirby LD (2014) *Handbook of Positive Emotions*. Guilford Publications.

Valle MF, Huebner ES and Suldo SM (2006) An analysis of hope as a psychological strength. *Journal of School Psychology* 44: 393–406.