

Psychological support in palliative care: A reflexive thematic analysis of relational space, awakening and meaningful living

Maria Davies-Edwards

mariadavies20331@gmail.com

University of Bath

Rachel Evans

University of Bath

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Abstract

Background: Psychological support is a core component to holistic palliative care. However, increasing pressures on hospice services highlight the need to ensure that psychological interventions are both accessible and effective. Exploring patients' and carers' experiences of psychological support within hospice settings is essential to promoting person-centred care. This study explored patients' and carers' experiences of formal psychological support in palliative care, including the enablers and barriers to accessing this support.

Methods: Ten semi-structured interviews were conducted with palliative care patients ($N=6$) and carers ($N=4$) who had received formal psychological support from hospices. Interviews were guided by a topic guide, audio-recorded, and transcribed verbatim. Data were generated using Braun and Clarke's (2021) six-step Reflexive Thematic Analysis, following an iterative and interpretative approach.

Results: One overarching theme was developed: *Being held ("like a group hug") – whole system approach*. Four themes described participants' experiences of psychological support: *A relational space to share guilt-free; An awakening experience – renegotiating priorities and values; Developing resources to live a meaningful life and Gratitude shaped by perceived limits of hospice resource*. Participants described how holistic, hospice-wide support created a sense of safety that enabled engagement with formal psychological support. Key enablers included compassionate interactions with hospice staff, supportive relationships, and support with practical and physical needs, such as caregiving responsibilities and symptom management – enhancing psychological wellbeing. Barriers included hesitation in asking for additional or adapted support due to gratitude and perceived resource limitations. Participants described how psychological support facilitated a recalibration of expectations of oneself, life and loss, encouraging relational connection and meaningful use of time.

Conclusions: It demonstrates the significant roles Clinical Psychologists can play beyond direct work. Findings highlight the importance of embedding formal psychological support within a broader culture of holistic, relational hospice care. Addressing barriers to access while strengthening hospice-wide psychological support may facilitate more equitable and person-centred palliative care.

Introduction

Palliative care

Across the UK, it is estimated that 90% of people need palliative care (Marie Curie, 2023). However, fewer than half eligible receive palliative care (Sue Ryder, 2021). Despite this significant unmet need, current funding for palliative care services has been judged inadequate, and has been identified as a particular issue in South-West England where there is an ageing population (Kallis et al., 2025). In contrast to other health services which are government funded, approximately two-thirds of hospice funding comes from charitable sources (House of Lords, 2024). This conflicts with the message of the National Health service (NHS) caring for individuals from 'cradle to death', with the later part of the commitment not adequately met (Salisbury, 2020). Therefore, a statutory requirement (All-Party Parliamentary Group on Hospice and End of Life Care) was introduced in the 2022 Health and Care Act to address unsustainable funding with duties placed on Integrated Care Boards to adequately commission services (National Health England, 2022). Aside from ethical practice, the efficacy of services is vital to consider when utilising limited resources in this context. This includes a focus on collaboration to promote person centred care at the end of life (Bellamy et al., 2022). Psychologists have the unique expertise in clinical and research skills that can enhance current palliative or end of life care (Haley et al., 2003). However, palliative care is underrepresented in health and medical research (Johnson et al., 2021).

The importance of psychological support for holistic care

Psychological support is a fundamental aspect of palliative care services (McInerney et al., 2021) and involves supporting people "to grieve the losses they are facing, to address difficult personal issues, to talk about their fears around death and dying and try to find the way to live knowing that they or their loved one is going to die" (Dorothy House, 2024). In line with clinical guidance, the psychological needs of both palliative care patients and carers need to be addressed to ensure that people can maintain a quality of life despite adversity (National Institute for Health and Care Excellence, 2019). These psychological needs can involve addressing mental health and spiritual needs, communication difficulties and developing coping skills to support adjustment for patients (Haley et al., 2003). Carers providing care for patients with terminal illness also have important psychological needs, which can lead to high levels of psychological distress, adapting to the short-term and long-term challenges of loss, and their own increased physical health problems (Haley et al., 2003). The role of carers in this phase of life is noted, both to support loved ones and to enable their own adjustment and meaning-making in a time of stress and loss (Ribeiro et al., 2021). As well as the moral argument for this, there may be a later service cost implication should prevention not be considered and carer needs go unmet (Schoo et al., 2025).

The Palliative and End of Life Care Priority Setting Partnership (PeolcPSP) (Best et al., 2015) gathered perspectives from patients, carers, and health professionals to identify key research priorities in palliative care. Among these, a priority for a better understanding of how mental health difficulties can be effectively recognised and treated, as well as to explore the benefits of psychotherapeutic interventions within palliative care services. So far, research has identified a focus on patient-centred care, care planning and a psychologically safe environment as important factors for patients and carers (Michel et al., 2023). Therefore, research plays a vital role in advancing both the quality of life for individuals in palliative care settings, including hospices, by driving ongoing investigation into the alignment of established research priorities and the realities of clinical practice.

Psychological support for palliative care patients and carers

Literature suggests that psychological support in palliative care often centres around reducing distress (Breitbart et al., 2004), through promoting patients' and carers' coping skills and facilitating acceptance and meaning making (Rodin et al., 2009). Approaching death, by nature, presents existential challenges to be supported (Zimmermann et al., 2014). Models of psychological support in palliative care revolve around addressing the psychological and existential

distress of patients and families. These include Cognitive Behavioural Therapy (CBT), Acceptance and Commitment Therapy (ACT) and Mindfulness-based interventions to build resilience and promote acceptance (Feldstain, 2024). Additionally, palliative care specific interventions such as Dignity therapy can be beneficial for those suffering with existential psychosocial-spiritual concerns, which might include hopelessness, feeling like a burden, loss of dignity, and depression (Saracino et al., 2019). Dignity therapy was developed in Canada to give patients a chance to record the meaningful aspects of their lives and leave a sense of self behind with loved ones, and has shown to be effective at reducing the suffering and distress of individuals at the end of their life (Cuevas et al., 2021). Culturally, death has been described as a 'taboo' topic in spite of the inevitability, but this has not been supported by research evidence. Instead, surveys suggest that 70% of people are comfortable talking about death and dying but talking about death is avoided due to fears others may be uncomfortable (Wilson et al., 2024). As such, how individuals face mortality can vary and requires a sensitive individual approach. This may include navigating potentially shattered assumptions afforded by existential avoidance and wider socio-cultural wellbeing determinants. Formulation-based psychological interventions can therefore compliment medical treatments for holistic care, by reducing psychological difficulties that may impact physical symptoms (Hudson, 2004). This includes in the support for carers to manage practical and emotional demands of this period (Moore et al., 2018) to reduce burnout (Lichtenthal et al., 2011). Importantly, tailored interventions are important for effective psychological care in line with the patient's and carer's preferences. This may include a combination of individual or group therapy, spiritual care, and therapies such as mindfulness-based interventions (Steinhauser et al., 2000). However, resource limitations can constrain the availability and impact of psychological support. As such, out of 116 UK hospices, only 16% of staff rated their hospice psychological service as adequate (McInerney et al., 2021). Furthermore, caregivers have described insufficient bereavement support despite existing guidelines (World Health Organisation, 2018), recommending continued support (Tarberg et al., 2019).

In line with previous research, a collaborative approach is required to understand the effectiveness of current interventions by exploring the experiences of those who have received them (i.e. patients and carers) (Kallis et al., 2025). However, gaps remain in the literature base to take this forward, as there is limited published literature exploring the lived experiences of patients, families and unpaid carers in the UK (Clark et al., 2024), and historically has been limited in the Southwest of England (Kallis et al., 2025). A qualitative research approach is suited with semi-structured in-depth interviews providing the means to explore this further. These are commonly used in qualitative health research to collect open-ended data that allows for the exploration of individual's thoughts, feelings and beliefs about a particular topic through delving into personal and sensitive issues such as those that arise in palliative care (DeJonckheere & Vaughn, 2019).

Using reflexive thematic analysis to explore lived experiences

Reflexive Thematic Analysis (RTA) is used to analyse and interpret patterns of meaning (themes) across a dataset, commonly interview transcripts (Braun et al., 2022). RTA has been used widely in qualitative health research, including palliative care (Braun & Clarke, 2024). It provides flexibility and depth, making it well suited to exploring complex and sensitive topics. It is particularly suited for exploring experiences that are deeply personal, emotional and contextual such as those related to palliative care (Braun & Clarke, 2024). RTA uses the researcher's reflective and thoughtful engagement with the data and the analytic process to develop themes. The reflexive element of RTA encourages the researcher's ongoing critical engagement with their own assumptions, positioning and influence on the research process (Braun & Clarke, 2019). In palliative care research, this may involve reflecting on the impact of professional and clinical experiences, personal beliefs about death and dying and emotional impact of participants sharing their experiences.

Study rationale and research questions

RTA is suited to interviews with palliative care patients and carers, providing the opportunity for the rich exploration of lived experience, emotional meaning and sense-making of palliative care experiences. Recent research has shown that there is an ongoing need to explore the perspectives of patients and carers in relation to the effectiveness of the psychological support they have received from hospices (Michel et al., 2023; Zavery et al., 2025). This study addresses this through the below research questions:

1. What are patient and carers' experiences of formal psychological support in palliative care?
2. What has been the enablers or barriers in accessing psychological support?

Methods

The project was pre-registered on the Open Science Framework on 17th October 2024. The Reflexive Thematic Analysis Reporting Guidelines (RTARG) were used to inform the write up of this project due to its development based on qualitative palliative care research (Braun & Clarke, 2024).

Study design

A qualitative design using semi-structured interviews was chosen in order to gather a rich and meaningful insight into participants' experiences. Braun and Clarke (2021a)'s RTA six steps approach were followed: 1) data familiarisation, 2) systematic data coding, 3) generating initial themes from coded and collated data, 4) developing and reviewing themes, 5) refining, defining and naming themes, and 6) writing the report.

Ethics approval

was provided by a Research Ethics Committee at the University of Bath (7287–20289). Through consultation with an officer at the National Institute for Health Research (NIHR), NHS ethical approval was not needed as hospice patients were not NHS-funded. Additionally, The Bath, Northeast Somerset, Swindon, and Wiltshire (BSW) Research Hub approved the project to recruit from Dorothy House Hospice and confirmed that NHS ethical approval was not

needed. Furthermore, the main researcher (MD-E) followed each of the individual hospice's ethical approval process which was unique to each hospice. The main ethical issues considered in this research project were participant informed consent, right to withdraw, confidentiality and risk of harm.

Consultation with hospices was completed prior to recruitment to inform the research questions but consultation with People with Personal Experience (PPE) was integrated throughout the whole research process. This included reviewing the topic guide to ensure the development of clear and sensitive interview questions, on the proposed procedures, and materials used, including the recruitment poster and debrief information guide. PPE were also involved in RTA by reviewing key themes from the interviews, as well as at the dissemination stage to discuss ways of sharing the findings in an accessible and meaningful format for patients, carers and other key stakeholders such as professionals in hospice or palliative care settings.

Participants

Those eligible to participate must have met the following inclusion criteria: they had to be proficient in English for interview, were over 18 years of age, and either were patients who were receiving palliative care from a hospice or were unpaid carers of an adult who had received or was receiving palliative care in a hospice setting, who had received professional psychological support. They needed to have the ability to provide informed consent, with an awareness of how their physical health could affect their participation. These criteria had been designed to be as broad as possible in order to capture a wide range of personal experiences.

Ten participants (six patients, four carers) were included in the study. Following a review of the data, this number was deemed sufficient to be able to effectively explore the research questions, with a near even split of patients and carers forming the sample. This was based upon using the Information Power model (Malterud et al., 2016), where the broadness of the aims, specificity of the sample (a specific period of life and circumstance) and quality of dialogue were considered, and participants provided depth in their experiences. Data saturation is inconsistent with RTA so this was not used (Braun & Clarke, 2021b).

Of the included ten participants, nine were female (five patients, four carers). All participants described themselves as White British using pre-defined categories. For the predefined age categories, three were aged 80+, three were aged between 60–69 and four were in the 50–59 age category. Two carers were children of a person in palliative care and two were spouses. Eight participants self-reported as heterosexual, with one patient and one carer who self-reported as bisexual. The most commonly reported life limiting illness was cancer, and all loved ones of the carers were deceased. Palliative care experiences included both inpatient hospice admissions and community hospice care, with the length of palliative care intervention ranging from three months to over two years. Psychological support received was one-to-one counselling ($N = 7$) or group interventions ($N = 3$).

Four individuals showed interest in the project but were not included as participants due to not meeting the inclusion criteria of receiving formal psychological support ($N = 2$) or due to a significant deterioration in health which meant they were unable to participate in an interview ($N = 2$).

Recruitment

Five hospices across the Southwest of England region signed up as gatekeepers to support recruitment by sharing information with hospice users, with participants recruited from three of five hospices. Potential participant could express interest in the project through contacting the main researcher (M.D-E) using telephone or email contact details, through a QR code or in written form. Hospices were provided with 'participant packs' each including a copy of the study poster, information sheet, consent form, contact details form and a freepost return envelope to the University. Those who met the stipulated inclusion criteria were invited to take part in the research project. The project was also advertised through social media (Linkedin) to increase recruitment efforts, but this was unsuccessful.

Procedure and data generation

Once participants shared interest in the project, they were offered to complete the interview online (via Microsoft Teams), by telephone call or in person to promote greater accessibility for participation in interviews. Flexibility in approach to data generation was needed due to the physical health needs of individuals in palliative care or the emotional sensitivity of topics discussed.

Participant information sheets and consent forms were distributed in advance, with signed consent obtained before the interviews and reconfirmed at interview. Interviews followed the topic guide which was developed specifically for this research (see supplementary materials). Any participant questions were addressed, and participants completed a demographic information form. Six interviews were conducted via telephone, while the remaining four took place online using Microsoft Teams. The researcher had no prior relationship with participants beyond organising interviews by phone or email. Interviews were carried out between July 2025 and January 2026, lasting an average of 62 minutes (range 41–84 minutes) with field notes captured during and immediately afterwards. Reflective listening and summarising were used to ensure accurate understanding, and participants were given the option to take breaks or skip questions if needed. All participants were offered a grounding exercise at the end of the interview and were offered a £10 voucher for their participation. A debrief form was emailed to participants following interview.

All interviews were conducted by the lead researcher (M.D-E) and recorded – telephone interviews using a Dictaphone and online interviews via Microsoft Teams. Recordings were transcribed verbatim and anonymised through the use of pseudonyms (e.g., P1, P2). Transcription was supported by a research apprentice (O.V). No participants chose to withdraw their data at any stage.

Data analysis

Paradigm and theoretical framework

A critical realist ontological stance and a contextualist epistemological approach were adopted for this project, recognising that participant’s experiences of psychological support in palliative care are grounded in real conditions of suffering, illness and loss but also shaped by context such as the healthcare environment, relational dynamics and social expectations. Furthermore, reality is seen as inherently subjective and influenced by the main researcher’s interpretation and their personal experience.

Reflexive thematic analysis

RTA’s theoretical flexibility aligns to this ontological stance and epistemological approach (Ahmed et al., 2025). It was an appropriate approach to generate common themes and patterns within experiences (Braun & Clarke, 2022). The six phases of RTA (Braun & Clarke, 2021a) are detailed in Table 1., however phrases were followed iteratively. A research apprentice (O.V) supported the process of data transcription and NVivo-15 (Zamawe, 2015), was used for efficiency, however the autocode feature was not adopted. There was a combined deductive approach informed by the research questions and topic guide, and an inductive approach whereby the data was open-coded. While latent coding informed theme development, semantic coding was also applied in instances where participants explicitly described their experiences, emotions, or preferences. As such, the analysis operated across both semantic and latent levels to address the research questions. This dual-layered approach supported both the faithfulness to participants’ accounts and deeper interpretative insight, enhancing the richness of the analysis (Byrne, 2022). Theme generation was completed on paper.

Dissemination

Findings from this study have been shared with participating hospices through the development and distribution of a concise, accessible leaflet available in both digital and print formats, summarising key insights for patients, carer and hospice staff. Consultation with PPE supported its development to ensure the findings were communicated effectively and sensitively to patients and carers.

Table 1
RTA six-phase process for data engagement, coding and theme development (Braun & Clarke, 2021a).

RTA step	Description of the stage	Researcher’s process
1. Data familiarisation and writing familiarisation notes	Researcher becomes deeply immersed and familiar with the entire dataset.	M.D-E listened to each interview recording twice while reading through the transcript. She recorded her initial thoughts on the second listen while also reflecting on what the interview evoked in her which she recorded in her reflexive journal.
2. Systematic data coding	Coding of an entire dataset using open coding (not from pre-existing categories), to produce initial codes to answer the research questions.	The entire dataset was coded by M.D-E to generate codes primarily using latent coding but also semantic codes, using a critical-realist perspective. In line with this stance and RTA, coding reliability was not appropriate as codes are actively produced by the researcher (Byrne, 2022).
3. Generating initial themes from coded and collated data	Developing patterns of shared meaning (themes) from coded data.	M.D-E printed out all the codes stored on NVivo-15 and grouped them into piles where there appeared to have a shared meaning. Ideas were discussed with her research supervisor (R.E), research apprentice (O.V) and PPE, and also recorded in her reflexivity log. Data extracts relevant to codes were reviewed and initial thematic maps drawn.
RTA step	Description of the stage	Researcher’s process
4. Developing and reviewing themes	A recursive process to generating and reviewing themes against coded data and the full dataset.	Initial themes were reviewed and further developed through the process of collapsing, splitting or discarding initial themes. Further thematic maps were developed and meetings with R.E and PPE explored relationships between themes and the boundaries of each theme.
5. Refining, defining and naming themes	Refining and naming themes to convey analytic meaning to articulate its “story”.	The final theme names and definitions were developed and refined. This step involved revisiting interview recordings to relisten to the segments quoted to ensure that the meaning had not been inadvertently misrepresented (Braun & Clarke, 2022).
6. Writing the report	A coherent analytic narrative integrating illustrative data extracts written into a report.	The final report and thematic map were produced. Final illustrative quotes from data extracts were chosen to demonstrate aspects of each theme.

Reflexivity

I (M.D-E) reflected on my role in this research, that my approach is shaped by both my professional and personal experience of palliative care. I identify as a White British female in her late twenties. Professionally I am a Trainee Clinical Psychologist, who works clinically with mental health, bereavement, patients with life limiting illness and their carers. Personally, I am a wife and a daughter who had cared for her mother during her experience of palliative care. From this personal experience, I developed a strong desire to explore research into the provision of psychological research in these settings. In order to keep awareness of my personal and professional experiences, attitudes and expectations I kept a reflexive journal and spoke openly with my supervisor throughout the research process. It was vital to notice and reflect upon the impact of these experiences on my interpretation and generation of the data, which was revisited frequently. I bring to this work a belief that people’s accounts of their experiences can provide meaningful insight into how psychological support functions in real-world contexts. However, I also acknowledge that these accounts are influenced by the healthcare environment, social norms, and my own interpretive lens as a researcher.

Results

MD-E organised data into one overarching theme and four themes, with accompanying subthemes as displayed in a thematic map in Fig. 1. The process of analysis included discussion with both the research supervisor (R.E), research apprentice (O.V) and PPE for a consensus approach, albeit M.D-E was responsible for deciding on the final themes and layout.

Interview participants are identified by code—ranging from P1-10 and indicated if they were a patient or carer. Patient and carer data were analysed and reported together, unless there was a clear exception for a particular group, due to the clear overlapping nature of their narratives, indicating experiences as hospice users. Both groups described similar experiences of accessing services, receiving support and navigating palliative care. This approach recognised that the level of support required is systemic and relational, as carers often play a central role in patient care, highlighting the need to examine the wider picture of care rather than viewing patients in isolation. Conducting separate analyses would have risked limiting the exploration of the relational nature of participants' experiences and limiting the development of themes that spanned both groups. For example, the overarching theme of a whole-system approach to hospice care was generated from the shared experiences of patients and carers, while the subtheme of emotional containment (1.1) illustrated how both groups sought to protect one another and other loved ones by concealing their own distress. Analysing the data together enabled these interconnected experiences to be identified and interpreted within the broader context of hospice care.

Additionally, integrating patient and carer perspectives aligns with palliative care guidance (National Institute for Health and Care Excellence, 2019) and hospice approaches e.g., Dorothy House (2024), which emphasises patient and carer support to better address shared psychological and practical needs. Furthermore, previous research such as Kallis et al. (2025) has used joint focus groups with patients and carers in hospices, demonstrating the value of capturing and analysing multiple perspectives together. This is particularly important given the recognised challenges in conducting research in this area, where incorporating multiple perspectives strengthens collaboration in shaping palliative care (Kendall et al., 2007). Therefore, combining patient and carer data was considered methodologically appropriate and aligned with both the research questions and the relational context of hospice care.

The themes developed through analysis are described in detail below, with a reflexive choice to present these in the order shown to demonstrate the process developed across participant accounts. Participants described being held by a consistent, relational and system-wide approach to wellbeing which was embodied in their experience of palliative care. The nuance of this experience is explored within four themes. The system wide approach offered by the hospices (overarching theme: *being held* (“like a group hug”) – *whole system approach*) enabled participants to feel safe enough to access and openly discuss emotionally challenging or perceived taboo topics in structured psychological support guilt free (Theme 1), which together created the conditions for deeper internal reflection on values to construct a meaningful life in the context of mortality and loss (Theme 2). This supportive environment and reflection facilitated the development of coping resources in psychological support, allowing participants to manage emotional, practical, and existential challenges associated with illness and caring (Theme 3). However, participants' awareness of the hospice as a finite, resource-constrained service also shaped their perception of support, with expressions of gratitude sometimes leading them to self-limit what they felt able to request or express (Theme 4). Taken together, this highlights, a nuanced dynamic in which participants experienced care as both deeply supportive, and at times, subtly restricted, illustrating the complex ways in which psychological support is both enabled and negotiated within this context.

Overarching theme – being held (“like a group hug”) – whole system approach

This overarching theme represented the strong emphasis on a whole systems approach experienced by participants when describing psychological support. Across all participant accounts, it was notable that participants began describing formal psychological therapy but moved quickly into the felt sense of the valuable support received from the whole hospice system, including nurses, doctors, and complementary therapists. This suggests that what participants experienced as beneficial psychological support was not solely a formal intervention, but an embedded, consistent approach by staff in everyday interactions to allow them to feel held psychologically. This holistic relational support embedded within hospices provided the safety to enable patients and carers to adapt emotionally, practically, and existentially to illness, step back from caregiving roles, and feel supported when approaching death and loss. Examples of how this was created included frequent check ins from staff, clear and consistent communication, which promoted efficiency and trust that all needs would be met e.g., staff ensured that a wheelchair was available for a patient after they discussed the mobility difficulties as a barrier to accessing a psychological wellbeing group. In the case of carers, this allowed them to step back from their carer role and to return to their original role e.g., of a daughter.

The hospice really felt like a group hug. It's the only way I can describe it because as I said, I felt held....it took me a few days to step back but ...they kept reassuring me that it was OK...I could step back....I could become a daughter again for that period in that the last few weeks and that again was not to be underestimated because I hadn't been able to do that, so that was amazing and I felt I could trust them. P6 (carer).

The volunteers and paid staff are great as if you're having a bad day, they see it all over your face and pull you to one side and check in and say, you know, is there anything I can do? P1 (patient).

Theme 1 – A relational space to share guilt-free

All participants shared how formal psychological support enabled them to speak openly in ways that were not possible elsewhere, sharing personal experiences that were heard and validated. The subthemes within this theme explore the spaces where support enabled participants to share their experiences in an open manner to reduce feeling alone with their distress. It was recognised that different support spaces had different functions but overall equated to individuals being able to share their experiences “guilt free”.

Subtheme 1.1 Emotional containment of distress within social relationships

Participants discussed the social constraints of speaking about death within personal relationships in their lives. This was framed as a “holding back” (P9) in order to avoid burdening others who may find the topic or their distress overwhelming. Therefore, participants often felt unable to be fully authentic within family roles or close relationships as they felt they would “hold back” sharing difficulties with loved ones, to avoid burdening others because they may find

disclosures distressing, or due to social expectations of handling life limiting illness or caregiving responsibilities and grief. They felt like they have burdened others enough (with their illness for patients or grief for carers).

I don't want to cause the family another burden. P1 (patient)

I can talk to my friends about things. I can talk to my family about things, but I kind of, ...hold back. P3 (carer)

Subtheme 1.2 “We are in the same shoes” (group therapy)

This subtheme is informed by patient accounts only as group therapy was only attended by patients. In these group settings, support was seen as a shared space that fostered validation, the mutual understanding of a shared experience which broke down barriers to contributing to the discussion around death and dying, which allowed them to confront mortality. There was not a sense of needing to protect others as they were in the same shoes.

Connecting with all kinds of people is interesting, but I think the fact you're in a place where people are in a similar situation to you that is important. P1 (patient)

Participants drew strength from witnessing others' resilience despite difficulty:

...Because you think you know they're coping. Why can't I? P1 (patient)

However, carers spoke of a desire to access group support for themselves to connect with others and enhance their psychological wellbeing:

I think for me that something that would enhance things would be something around connection with other people who've gone through something similar... I had this question in my mind....'where do all the widows go?' How do I find other people like myself who are...going through this as well...Just other normal people to have that connection with. I mean, my friends have gone through grief, but nobody's lost a husband. P3 (carer).

Subtheme 1.3 “Being able to unburden in a kind of no holds barred way” (one to one therapy)

One-to-one support was experienced as a necessary relationship with an external and neutral person to share openly with. This practitioner is constructed as a significant relational figure – described as a “helping hand” or an important “surrogate person”, indicating the development of a supportive and trusting relationship that was attuned to the individual's internal world and where the individual could be truly open without fear of distressing the other as they are seen as external to the individual's world.

She came into my life as a counsellor, that she's a kind of surrogate...A surrogate someone that I can really talk to and articulate things which I can't generally often do with some of the people around me. P4 (patient).

There was an apparent sense of safety in sharing openly due to a reduced responsibility for the listener's emotional response, which reduced the need for self-censorship. Within this context, participants moved towards increasingly open and unrestrained disclosure, including sharing unspoken experiences and perceived taboo topics relating to death and sexuality in the context of life limiting illness, describing the therapeutic space as enabling them to “unload” their distress with the practitioner.

It really is for me, good to have somebody that I don't know have a conversation with me. I mean, in the sense of it's not like a friend or a relative. It's very good for me to have someone outside that to have a conversation with. P4 (patient)

To say what you know, whatever it felt like.... That's what really helped...being able to unburden in a kind of no holds barred way. P3 (carer)

I can load off a lot of things, you know, what is on my chest P8 (patient)

What is distinctive is how the therapeutic space disrupted everyday expectations to “hold it together” and protect others, instead fostering connection, reduced isolation, relief and authenticity. Within this space, they felt able to voice fears, reflect on mortality and process end of life concerns openly, reducing isolation and validating experiences.

Her visits been able to feel comfortable in myself and not having to.. answer to anybody, if that makes sense? I can just be myself. P10 (patient).

Just somebody to...*give* me permission to deal with it in my way P3 (carer).

Theme 2 – An awakening experience – renegotiating priorities and values

Across patient and carer accounts, a relational space, in group and one-to-one therapy settings, prompted an awakening experience. This process involved the permission to enact self-compassion leading to the identification of their own needs and their values for a good life, in the context of own mortality or in the loss of their loved one. This enabled reflection on their personal values and priorities to live a meaningful life. This theme shows how psychological support functioned as a catalyst for meaning making by, legitimatising self-reflection through self-compassion and a sense of external “permission” by a therapeutic space to prioritise the self and evaluate values, beyond illness or caregiving roles.

Subtheme 2.1 Changing patterns of self-relating - “I just decided, by the end of my life, maybe I just deserve a little bit more”

Reflection emerged as a process through which patients and carers revisited prior ways of coping and patterns of relating to the self. Participants described a shift towards greater kindness towards themselves, including reflecting on personal values and prioritising their own needs. This was facilitated through psychological support as a tool to give permission to patients and carers to enact self-compassion. The supportive, open space that psychological support and the supportive therapeutic relationship provided, enabled patients to recognise their own emotional needs in relation to disease progression and complex physical health needs, while carers described adapting to a new carer role and maintaining other aspects of life. Some patients and carers reflected how they would prioritise others' needs, at the detriment of their own:

I was usually a people pleaser. P8 (patient)

I wasn't a priority. P3 (carer)

In the reflective space provided by formal psychological therapy, therapists gave permission for individuals to develop self-compassion to recognise and prioritise their own needs:

It was just like recognising and putting me in the middle rather than putting me on the edge with all the other stuff. P7 (carer)

I just decided, by the end of my life, maybe I just deserve a little bit more. To be kinder to myself. P8 (patient)

Subtheme 2.2 – Finding meaning in life away from illness

Across accounts, confrontation with mortality through palliative care – whether their own or that of a loved one – was experienced as prompting a critical reappraisal of life:

Palliative care... it's made me go over my life. P10 (patient)

This awakening experience was constructed as an essential acceptance of mortality, not as a final state but as an ongoing orientation that allowed participants to reduce death anxiety and reposition their relationship to mortality, with a perceived reduction in the need to always carry one's own mortality, or to temporarily set aspects of caregiving and emotional burden to one side. The psychological support provided the reflective space to explore this, where rather than being focused solely on illness, participants emphasised the psychological support allowed the prioritisation of values around the illness.

(when discussing a loved ones' mortality)...it is OK to package it up...*and*...put over there and park it. P7 (carer)

I think it's an overall acceptance of where you're at and what your situation is and how to...live with it...And what you're willing to live with and what you want to put to one side. P9 (patient)

This suggests that reflection functioned as a means of negotiating between illness and the preservation of a broader sense of self in order to live in line with what is important to them, seeing the formal psychological support as a space to process this. The permission given for patients and carers to reconsider their values and priorities supported a deliberate consideration of what mattered for the present and for the future. For patients this included engagement in meaningful activities in the life they had remaining, for carers this looked like redefining a life after loss including maintaining bonds with the loved one (e.g., identifying memorable items to keep) while continuing to plan for the future such as solo travelling.

Gives you that opportunity to sort out for yourself what you want. P9 (patient)

I identified what was important to me about the relationship I'd had with *husband* and she (*therapist*) gave me some frameworks of how to think about that...identifying one or two things that were the essence of him that I wouldn't part with and ...let go of the trivial everyday stuff like his shirts...easing me into the process of grieving and letting go and also recognising where ...I am in that journey and some of the analogies she gave me were really helpful, which was around how grief doesn't go, we grow around it...I've spent quite a lot of time trying to redefine my life now. P3 (carer)

Theme 3 –Developing resources to live a meaningful life

Internal reflection and the identification of needs highlighted the need to develop appropriate resources through psychological support to live a meaningful life. This involved the building of strategies (e.g., emotion regulation skills, problem solving skills) while managing uncertainty for the future. Opportunities to navigate complex emotions (e.g., grief, fear and guilt) were supported by the development of emotional coping strategies. Validation, cognitive reframing and the introduction of alternative perspectives enabled participants to manage difficult, unpredictable and painful experiences.

Not everything's my fault, it turns out....a lot of it's not in my control....wasting time on worrying about it. there's nothing I can do in this situation. you're always going to feel guilty because it's just that it's just how it, like, be accepting of that. It's just like, OK, that is, that is a feeling that is happening. P7 (carer)

I'm just looking at it from other perspectives. P7 (carer)

Changing your mindset about it, it does mean that you can deal with things physically better. P9 (patient).

Psychological support also facilitated the development of practical strategies for managing day to day challenges (e.g., carer responsibilities, health needs) and as a space to reflect on complex decision-making processes (e.g., end of life planning arrangements, selling property after a loved one has died), which seemed especially salient in carer accounts albeit present in some patient experiences also. Support also included the education on the dying process, reducing anxiety for participants. Participants described shifting from merely surviving, to regaining a sense of control to engage more actively with life and increasing their overall functioning.

She helps guide me to sort out problems. P10 (patient)

But she just helped me to put it into small chunks. P5 (carer)

I'm attempting to sell my house, so I've got to get rid of things and even with that she kind of gave me some frameworks of how to think about that. P3 (carer)

Carers reflected that psychological support allowed them to manage the uncertainty for a future without their loved one:

And she says well, it's like building a jigsaw...start with your corners. And you...fill in bits and some bits are just going to be a bit blank at the moment, and that's OK. P3 (carer)

It was that that reassurance that there is life and another chapter coming up...It can still be exciting times as well. P5 (carer)

This theme demonstrates how formal psychological support supports both emotional and practical adaption, enabling participants to reduce anxiety, tolerate uncertainty, and act in line with their values within the context of illness, caregiving and mortality.

Theme 4 – Gratitude shaped by perceived limits of hospice resource

Across participant accounts, expressions of gratitude were closely intertwined with an awareness of the hospice as a finite, resource-constrained service with patients seeing hospice admittance as an “opportunity” (P1). Participants, particularly patients, frequently positioned the support they received as generous and valuable, often emphasising their knowledge that hospice funding is charity based.

I felt, just felt I'd had enough, so I decided I wouldn't have any more treatment...and then they gave me the opportunity to go to the hospice. P1 (patient)

I am really grateful they have this group P8 (patient)

I've been lucky because I was allocated *counsellor... I don't know how accessible it is and I think it, like so many things...it is financially based. P10 (patient)
This awareness appeared to shape how participants engaged with care, fostering a sense that additional needs or requests may be unreasonable or burdensome for the service. For some, this was reflected in a reluctance to suggest improvements, even when barriers to accessing psychological support were evident such as when discussing adaptations for an in-person group:

Of course I would prefer in person, but considering that, for example, a lot of people are probably in a similar condition than I am, that they can't really leave a house....maybe it would be useful if they offer online and in person....But you know, the hospices rely on charities, so ...they are relying on donations, it is already wonderful that they could offer this opportunity. So, maybe it would be too much to ask. P8 (patient).

They obviously would like to like to offer more services to more people but they can't because of funding....But it isn't accessible...they don't have the resource. P4 (patient).

Additionally, some participants spoke of wanting to “give back” to the hospices directly and through volunteering or contributing to the present research.

And I think it does help you to understand that they need lots of money and to help fundraise for them. P5 (carer)

I'm really happy and I hope I have been helpful for you going forward. P10 (patient)

Several participants either declined financial compensation for participation, expressing a desire for resources to be directed toward those perceived as more in need or if they did accept compensation, they showed strong gratitude towards it, despite the researcher informing them that the payment was not associated with the hospices:

It is more important for you to use money elsewhere. P6 (carer).

Thank you. Thank you very much. That's really generous of you for the gift cards, so thank you. P10 (patient)

This pattern suggests that gratitude functioned not only as an emotional response to the support received, but also as a mechanism shaping what participants felt able to express or request and a desire to participate in this research to “give back” and not motivated by the financial reward. While the hospice was experienced as supportive and containing by all, this theme highlights a barrier whereby participants may self-limit the sharing of their unmet needs. In this way, gratitude operates within a broader context, reflecting participant's sensitivity to resource constraints and contributing to a nuanced understanding of the contextual lens that care is experienced, revealing a subtle barrier to expressing needs.

Discussion

This project aimed to explore the experiences of formal psychological support in hospice settings for patients and carers, along with the enablers and barriers in accessing this support. RTA was used to explore these experiences, and it provided the flexibility and depth to explore this complex and sensitive topic area, as it is suited to exploring experiences that are deeply personal, emotional and contextual (Braun & Clarke, 2024; DeJonckheere & Vaughn, 2019). It provided the opportunity for the rich exploration of lived experience, emotional meaning and sense-making of hospice care experiences. This approach was also appropriate due to the researcher's own personal experience as an unpaid carer of a patient in palliative care, with RTA encouraging the ongoing engagement with their own assumptions, positioning and influence on the research process. More widely, RTA is suited to explore palliative care experiences as all individuals carry their own personal beliefs about death and dying, and can be impacted by participants sharing their emotive experiences (Braun & Clarke, 2019).

Participants described experiences of formal psychological support offered by hospices. However, it was highlighted that psychological support in hospice care operates not as a discrete intervention, but as a relational, holistic system, which enables individuals to access formal psychological interventions and to develop a connection with therapists and peers for emotional processing, values identification, and adaptation through the development of emotional and practical coping resources, all shaped by broader social and cultural contexts. The PeolcPSP (Best et al., 2015) identified patient-centred care and a psychologically safe environment as important factors for patients and carers in palliative care (Michel et al., 2023). These experiences are in line with the essence of palliative care, where it should follow a holistic, person-centred approach that focuses on comfort, dignity and quality of life at the end of life, including the support for loved ones (Hackett, 2017). With authors suggesting that even when people go through the hardest situations, having people around them that gives them the experience of being cared for and held makes the difference in their ability to cope, describing this as the power of everyday heroes (Ampaw-Farr, 2025).

Participants shared how formal psychological support enabled them to speak openly in ways that were not possible elsewhere as “a relational space to share guilt-free” (Theme 1), facilitating this support. Surveys have suggested that although people report feeling comfortable talking about death and believe society should be more open about it, there is a clear gap between attitudes and behaviour. In reality, relatively few people (14%) have had discussions regarding serious illness and dying, and while individuals may feel personally comfortable, many perceive that society as a whole does not talk openly about death, which may discourage proactive conversations (Nelson et al., 2024). Previous qualitative research has suggested that patients and carers keep their feelings from their loved ones to protect them (Kallis et al., 2025). As stated by Dame Deborah James “death is life’s last taboo” (Rowcroft Hospice, 2022). A century ago, most individuals in the UK died at home, which fostered a cultural familiarity with death and the dying process. Death was not concealed within hospices or hospitals, but rather a visible and understood part of life (Cock-Starkey, 2025). In modern society however, this familiarity has reduced significantly, as dying is often removed from public view and held within health care settings (Department of Health, 2008). Therefore, Clarke (2020) describes how death remains an inherently distressing subject, representing one of the most profound forms of existential anxiety experienced by human beings. Unlike other living creatures, humans possess an acute awareness of their own mortality. This awareness involves the anticipated loss of connection to relationships, experiences and aspects of life that are deeply valued, making it psychologically challenging to confront.

Within Theme 1, the subtheme of emotional containment of distress within social relationships (1.1) captured participants experiences of censoring their difficulties with loved ones due to worry of making others uncomfortable by talking about death or due to the fear of burdening others. Survey literature supports this and suggests that whilst most people are comfortable to talk about death and dying, it is avoided because of perceptions that others may be uncomfortable, maintaining the perceived notion that it is taboo (Wilson et al., 2024). The concept of “burden” refers to the perceived and actual strain experienced by both patients in palliative care and their informal carers. Mcpherson et al. (2007) highlights the importance of self-perceived burden, whereby patients may view themselves as emotionally, physical or financially taxing to others as functional decline and increasing dependence can undermine their sense of autonomy and dignity and is correlated with psychological and existential concerns. This self-perceived burden is also apparent in carers, where there is a tension between carrying a burden and feeling like a burden. Carers can experience significant emotional and practical strain but feel unable to express this openly to protect the person they care or cared for (Lilleheie et al., 2021).

It therefore appears that mutual protection creates silence where both carers and patients often try to shield one another and the loved ones around them due to fear of distressing one another. This level of emotional containment inhibits disclosure and hinders the emotional adjustment to trauma or illness (Lepore, 2001), which risks isolation and disconnection. This may highlight the need for a connection with a “surrogate person” as described in this study. Linking to Yalom (1980)’s existential givens, existential isolation stems from experiences relating to death and the awareness of our own mortality as one of the loneliest human experiences. He posits that all human beings enter and leave life alone. A life limiting diagnosis does not only force an individual to confront their mortality but also for those around them to realise their own e.g., “If he can die, then so can I” (Yalom, 2008). While existential isolation is a part of the human experience, meaningful human connections such as peer support and therapeutic relationships can bridge this separation (Storey et al., 2022; Tang et al., 2022; Yalom, 1980).

Patients and carers have feelings of grief for the loss of functioning, life and future which feels isolating and needs to be recognised by others. Participants spoke of spaces through the hospice where their pain and experiences of grief and loss can be shared with others. Some patients engaged in group therapy interventions, which were seen as valuable spaces to feel comfortable to talk about death and dying as they were all in the same shoes as one another (subtheme 1.2), providing validation and resilience. Kessler (2019) writes, “having our pain seen and seeing pain in others in a wonderful medicine for both body and soul” (p.18). They write that sharing one’s and witnessing another’s pain, sense of loss and grief creates deep connections to one another and softens the existential isolation that occurs like in group therapy experiences as shared by participants.

For one-to-one therapy, patients and carers spoke of feeling able “to unburden in a kind of no holds barred way” (subtheme 1.3). A relationship with an individual outside of their internal world reduced self-censorship and provided the space to share unspoken experiences openly with another, such as their own ways to manage grief. This experience was crucial for participants to improve their connection with another, have their grief witnessed authentically and ease existential isolation (Yalom, 1980). Kessler (2019) writes that “Each person’s grief is as unique as their fingerprint. But what everyone has in common is that no matter how they grieve, they share a need for their grief to be witnessed. That doesn’t mean needing someone to try to lessen it or reframe it for them. The need is for someone to be fully present to the magnitude of their loss without trying to point out the silver lining” (p.41). Kallis et al. (2025) have showed those in palliative care contexts value the space offered by formal psychological support to offload to a professional rather than a family member.

Meaningful engagement with life can further soften existential isolation and a second existential concern of meaninglessness (the human need to establish a sense of meaning in one’s lives) (Yalom, 1980). The awareness of the precariousness of life and death prompts both patients and loved ones to an ‘awakening’ experience (Theme 2). There is a shift from an everyday mode of living (where individuals spend most of their life focused on mundane concerns with an unconscious avoidance of mortality) to an ontological mode (a heightened state of awareness of mortality which prompts the more intentional choices about how to live). Yalom (2008) spoke of how these profound awakening experiences (such as life limiting illness, death, grief) often shocks people out of their everyday mode into an ontological mode, where they can reflect on meaningfully living their remaining life. This proposes that when pain and suffering are encountered, it prompts individuals to look inward, challenging and drawing on their reserves to find meaning in this suffering (Reneau & Eanes, 2022).

Experiences of serious life limiting illness bring us face to face with our inherent fragility (Reneau & Eanes, 2022). This prompts the process of reimagining ourselves into an unknown future while we grapple with profound feelings of sadness and loss. Wheatley (2011) suggests that when faced with fear or grief, humanity has only two fundamental choices: “we can turn away, or we can turn toward. Those are the only two choices we have” (p.16). Turning towards one’s pain involves self-reflection and the willingness to face our vulnerability to identify what necessary self-work is needed for progress (Reneau & Eanes, 2022). The psychological safety that the whole hospice support provided facilitated the access of formal psychological support to have the opportunity to gently reflect on the impact of one’s or a loved one’s life limiting illness. Reneau and Eanes (2022) suggests that only once crisis (e.g., serious health care

needs) is managed, can the process of introspection be facilitated. They suggest that engaging in introspection allows individuals to take some control of one's thoughts and ascribe meaning to an uncontrollable situation such as a life limiting condition. Yet, this process can only be achieved when individuals are willing to look within themselves where pain and distress linger, and a supportive connection with others in a similar situation or with a therapist provided the safety to do so.

Introspection provides learnings of past patterns of self-relating. Individuals can choose to avoid their deep pain by distracting themselves, numbing their feelings, or denying their experiences. Alternatively, they can face that pain with compassion, giving it their full attention and allow themselves to feel it exactly as it is (Kumar, 2005). Participants shared experiences of negotiating patterns of self-relating (subtheme 2.1) which resulted in the letting go of habits of thinking that distanced them from experiencing the fullness of life. Wheatley (2011) explains that compassion creates space for reflective thinking, enabling individuals to act with greater wisdom and courage. Within the context of individual and collective grief, prioritising compassion over judgement represents opportunities for individuals to construct meaning from their lives and to live in line with their values, resulting in personal change and liberation (subtheme 2.2). Within hospice care contexts, letting go may involve relinquishing previously held expectations for the future, fostering acceptance of present circumstances, while balancing it with feeling able to set mortality briefly to the side to be able to shift back to everyday mode. What remains is the individual's (patient or carer) capacity to construct and ascribe meaning to their experiences, even in the context of advanced illness and uncertainty (Reneau & Eanes, 2022).

Acknowledging and naming pain is the initial stage of meaning-making, an importance process as we are a meaning-making species (Reneau & Eanes, 2022). This meaning making is an adaptation to a new loss which involves constructing a new reality, to acknowledge what was lost, make sense of the loss and rebuild a sense of self in the new reality (Reneau & Eanes, 2022). Breitbart et al. (2004) discussed the significance of meaning making to cope with the emotional and existential suffering in the face of death, with psychological practitioners having a role in the promotion of personal agency as individuals are confronted with death. This may promote the development of post-traumatic growth, the process of positive psychological change and personal growth that may occur as individuals cope with a life-limiting illness – including changes in priorities toward what matters most (Bernard et al., 2022). This process can also be true for carers, as the death of a loved one can serve as a powerful catalyst for posttraumatic growth, where individuals live more meaningfully by re-evaluating their priorities and values (Taylor, 2020). Even in the most direst circumstances, people seek out their purpose in life. Frankl (1971) described that all human beings need to establish a sense of meaning in their lives, which is unique to them and a sense of meaninglessness leads to psychological distress.

Internal reflection and the process of meaning-making required the development of emotional and practical coping resources through formal psychological support. This is situated within the literature that suggests that psychological support promotes acceptance and meaning making by strengthening patients' and carers' coping skills (Rodin et al., 2009). This includes the development of cognitive coping skills (Zimmermann et al., 2014) and navigating the complex, and often emotional end of life decision making processes such as advance care planning (Moore et al., 2018). NICE recommend that practical and emotional resources for carers are important, allowing them to adjust to caregiving roles and emotional demands while navigating a meaningful life for themselves (Brownie et al., 2014; Tarberg et al., 2019). The development of coping resources to resolve practical and emotional difficulties is crucial to navigate stressors that are complex, emotionally intense and uncontrollable such as in contexts like palliative care (Baker & Berenbaum, 2007).

It is important to acknowledge factors impacting on the positionality of the participants which shaped their narratives, meaning making and social context, which consequently formed theme four, whereby gratitude was shaped by the perceived limits of hospice resource. It was generated that patients and carers are not merely uninfluenced by the sociocultural situations they are in and their awareness of the limited hospice resources influenced their experience of care received and ability to be able to request adaptations due to their awareness of the majority of hospice funding coming from charitable sources. In this current research, theme four was particularly salient in the patients' experience of palliative care, as reflected in the illustrative quotes included within the results section. Literature suggests that gratitude for hospice support extends beyond the appreciation of limited resources. Enabling participants to be grateful in the context of difficulty, may be influenced by the hospices' ability to alleviate distressing symptoms such as pain, breathlessness, nausea and anxiety (Husic et al., 2025). For patients, gratitude commonly arises when care is experienced as holistic and person-centred, with attention given not only to physical needs, but also recognising and managing psychological concerns. In this way, care may be appreciated because it affirms dignity and personhood at a time when illness can otherwise reduce individuals to their life limiting illness (Chochinov, 2002).

Among carers, gratitude is similarly associated with the emotional and practical support offered by hospice teams while caring for a loved one. This was present in the current research but to a lesser degree than generated from patient accounts. Nevertheless, relevant carer illustrative quotes are included in supplementary materials and highlight that gratitude was still present in carers' accounts. Hospice involvement can mitigate caregiver pressures through expert guidance, respite and emotional support (Hudson et al., 2010). Carers may therefore express gratitude not only for the direct care given to the patient, but also for the recognition and support of their own needs. Therefore, from an ontological perspective, gratitude emerges not merely in response to service delivery, but through the reestablishment of a mode of being in which suffering is accompanied while individuals are seen in their entirety (Arantzamendi et al., 2023). The sense of gratitude for services may function as an interpersonal bridge that enables patients and carers to accept psychological support on offer and promote help-seeking tendencies (Day et al., 2020). While suggesting that gratitude may facilitate the acceptance of psychological support, it may also create barriers to voicing unmet needs or requesting changes such as in some participant accounts e.g., request for online group options due to physical health limitations. When support is perceived as generous due to scarcity of resources, individuals may feel they should accept what is offered rather than request adaptations (Goodrich et al., 2025).

Several of the processes identified in this research such as emotional processing, reflecting on values, finding meaning and developing resources, are not unique to palliative care. These are important components of widely used therapeutic approaches such as CBT, ACT and mindfulness-based interventions in mental health care. This suggests that many of the psychological skills and mechanisms used in other areas are transferable to palliative care. These include cognitive reappraisal, psychological flexibility, and present moment awareness, all of which are relevant for presentations such as anxiety, depression,

adjustment difficulties and chronic illness more broadly. This aligns with literature suggesting that existing psychological models can be adapted within palliative care settings (Feldstain, 2024).

However, the themes produced in this research also highlight specific considerations of psychological support in palliative care. One key aspect relates to the emotional containment within social relationships and the worry of burdening others, as topics around death, dying and loss were perceived as too difficult to share. In this context, psychological support functions as a relational space, allowing patients and carers to share distress, guilt and fear “guilt-free”. A space that may not be available within family or social networks. In addition, the analysis emphasises the importance of directly confronting death, dying and loss. While mortality may be discussed in other areas, in palliative care this is immediate and unavoidable. Feldstain (2024) suggest that this death awareness forms a central component of care rather than a secondary consideration in these settings. Additionally, the importance of holistic, whole-system care in enabling and sustaining psychological support appears to be particularly important in palliative care. The embedding of psychological interventions within a multidisciplinary model of care is essential, as emotional wellbeing is closely intertwined with physical symptoms and existential concerns (Hackett, 2017). Closely linked to this is the importance of working relationally with both patients and their families, to support distress, meaning-making, communication and anticipatory grief. Interventions such as Dignity Therapy illustrate the specificity of psychological interventions in palliative care to address existential concerns, dignity and legacy building (Cuevas et al., 2021).

Implications

The analysis suggests that participants’ experiences are broadly consistent with the aims of contemporary hospice approaches to holistic, person-centred palliative care, in which psychological wellbeing is considered integral to good quality of care (McInnerney et al., 2021). A key implication is the value of a whole hospice model of care to support psychological wellbeing by providing a psychologically safe care environment (Michel et al., 2023). As developed from participants’ accounts, psychological support is not only seen with psychological practitioners such as psychologists and counsellors but can be embedded across all staff roles and seen as clinically meaningful. Everyday interactions with all health professionals may foster safety, dignity and emotional support. Psychologists offer valuable clinical and research expertise in this by strengthening palliative care services through training staff in compassionate communication (Kallis et al., 2025), recognising distress, and responding to existential concerns for patients and their loved ones, strengthening their care even when specialist psychological support is limited (Feldstain, 2024; Haley et al., 2003). For example, nurses have reported a desire for further training in psychological support to enhance their practice (Haley et al., 2003; Zavery et al., 2025). However, in recent years it was revealed that only 19% of hospice have in-house access to a clinical psychologist with suggestions that provision of psychological care would be strengthened if there was further access to adequate training and supervision by those that hold expertise such as psychologists (McInnerney et al., 2021).

Nevertheless, formal psychological support still has a role to play in providing a unique space to share openly, reflect on oneself and values while developing resources to live meaningfully. However, limited funding and resource pressures may constrain access to specialist psychological support, despite its apparent value. Therefore, alongside maintaining a multidisciplinary hospice model to support psychological wellbeing, further investment is required to support the provision of specialised psychological support (McInnerney et al., 2021). These findings have implications for service development in line with public interest. For example, surveys have found that the public believe that palliative care should be a priority for health services and given equal priority as care for people in other stages of life (Marie Curie, 2021). A further disparity has been observed in palliative care research, which has historically received less funding than research focused on the prevention and cure of disease (Higginson, 2016). However, the NIHR has identified this imbalance and introduced initiatives aimed at improving funding and support for palliative care research (Thomas et al., 2024). Challenges associated with palliative care research is due to the nature of the vulnerable populations and the associated ethical considerations, rapid health decline and recruitment challenges (Barclay et al., 2019). However, the present research has demonstrated that it is possible to complete research in this area, and in gaining an insight of patients and carers’ experiences of interventions as recommended by the NIHR (Higginson, 2016).

It has been suggested that research in this area can be in part constrained by public and professional reluctance to engage with conversations around serious illness, dying and death (Chen et al., 2014; Kallis et al., 2025). This has particular relevance within the current UK context, where debates regarding assisted dying continue, with a proposed law to legalise assisted dying in England and Wales (Terminally Ill Adults (End of Life) Bill) (UK Parliament, 2026). It raises the question - how can society make decisions that are life and death if death itself remains difficult to discuss socially? This reinforces the need to normalise conversations about mortality, distress, values, meaning and preferences at the end-of-life and to move the topic of death away from being handled only by professionals (Wilson et al., 2024). Therefore, adequate palliative care is important now more than ever, with calls from a coalition of major UK hospice charities to reform care (Hospice UK, 2026; Sky News, 2024). A key argument against legalising assisted dying in England and Wales is that universal access to high quality palliative care is inconsistent, with individuals entering into a ‘postcode lottery’ of care in their most vulnerable moments of life (Health and Social Care Committee, 2026). Therefore, there are significant ethical considerations surrounding the legalisation of assisted dying. These include systemic failures in care, limited psychological provision, and the fact that resources capable of alleviating much of an individual’s suffering are not universally available. As a result, a person’s decision may be influenced not solely by their condition, but by society’s failure to provide the care, dignity, and support necessary for life to retain meaning at the end of life (British Medical Association, 2021; Sky News, 2024).

As the discussion of assisted dying has shown, the relevance of palliative care is for everyone. In *The Daily Stoic* (Holiday & Hanselman, 2016) it is suggested that becoming aware of one’s mortality may encourage the reassessment of priorities and a focus on meaningful actions, relationships and fulfilment. It posits the awareness of one’s death as a motivating force that can inspire people to live more purposefully:

Have you ever heard some ask: ‘what would you do if you found out tomorrow you had cancer?’ The question is designed to make you consider how different life might be if you were suddenly given just a few months or weeks to live. There’s nothing like a terminal illness to wake people up. But here’s the thing: you already have a terminal diagnosis. We all do. As the writer Edmund Wilson put it, ‘Death is the one prophecy that never fails’. Every person is born with a death sentence...Once you realise this, it will have a profound impact on what you do, say and think (p.376).

Overall, this analysis supports the importance of psychological care that includes formal psychological therapy but is also embedded within health care services, that recognise the needs of both patients and carers throughout illness, dying and bereavement (Bellamy et al., 2022; Zavery et al., 2025). However, it highlights the contextual impact of healthcare resource and societal impact.

Limitations and future research

While there were strengths to this project, particularly in its novel approach to exploring a hard-to-reach area (Chen et al., 2014), there are also limitations and suggestions for future research. Approaching dying and death by nature presents existential challenges to be supported (Zimmermann et al., 2014), however these were not explicitly explored during interviews. Two participants shared that they identified with a religion (Christianity) but the role of this and participants' spiritual beliefs within their experiences of palliative care was not explored during interviews. This frame of reference may influence themes within this analysis due to the influence of religion and spirituality on beliefs about death, dying and greater meaning in life (Pentaris & Tripathi, 2020). Future research could ensure that explicit questions exploring these could be included in the interview topic guide as research has shown that religion, belief and spirituality are important for patients and loved ones when facing death by providing a sense of comfort, security, meaning-making and closure (Breitbart et al., 2004; Pentaris & Tripathi, 2022).

Additionally, previous research has suggested that member checking strengthens the credibility of qualitative analysis by ensuring that the developed themes accurately reflect participants' intended meanings (Shenton, 2004). However, the use of member checking is embedded within the assumption that there is a true truth of participants' experiences that we can access if we minimise the researcher influence on the analysis (Smith & McGannon, 2018), which sits conceptually inconsistent with RTA (Braun & Clarke, 2023). Instead, member reflections as a Big Q alternative to member checking could have been used, where participants are invited to provide further insight on the analysis to offer additional reflections and to generate further data on the topic (Tracy, 2010). Nevertheless, this research has provided insight into experiences into a complex research area that can face many barriers area due to ethical considerations due to the vulnerability of participants (due to serious illness or grief), unpredictable physical health needs and a high risk of attrition (Chen et al., 2014; Kallis et al., 2025). This research, however, reflects only the experiences of those who have received formal psychological support. There is a need to capture the experiences of patients and carers who have been unable to access psychological support, as these individuals have reported to feel abandoned by healthcare providers in other research (Kallis et al., 2025).

Furthermore, the sample has several limitations that should be considered. The sample lacked diversity across certain demographics, particularly ethnicity, although this reflects the ethnic diversity of the South-West of England (Gov.uk., 2022). Future research should explore the experiences of individuals from a wider range of ethnic backgrounds. In addition, as participants were recruited through hospices, all had received specialised palliative care, further studies could examine the experiences of those who have not accessed this support. Additionally, participants had all received psychological support, which excludes the perspectives of individuals who have not sought or have been able to access support. This may result in a more help-seeking viewpoint being overrepresented, while barriers to access or disengagement from services are underexplored. This limitation may have been further influenced by the hospices acting as gatekeepers to the research. Hospices had some choice of who was invited to take part, potentially favouring individuals who were more stable and more positively engaged with services at the time of recruitment. As a consequence, certain experiences – particularly those more complex or critical may be underrepresented. Additionally, there is also potential for self-selection bias, as individuals who choose to participate may have more positive experiences than those who decline. While, RTA does not aim for complete generalisability, the transferability of findings to other populations is therefore limited. Building further on this, as cancer was the primary diagnosis for most participants accessing hospice services, future research could explore experiences of those with other life-limiting conditions. These factors are important to consider as health inequalities have been observed in hospice settings, where patients without cancer, ethnic minorities and those from the LGBTQ+ community are underrepresented (Tobin et al., 2022).

Quality practices and reflections on the research process

In line with the RTARG (Braun & Clarke, 2024) M.D-E's reflections on the research process and practices were supported by the completion of a reflexive journal across the research process. This documented analytic decisions, evolving interpretations and personal reflections and assumptions. This was particularly relevant due to her experience as an unpaid carer and professional experiences of working in health settings, which shapes the engagement with the data. This journal allowed for an audit trail of how codes and themes developed over time. Initial coding prioritised participants' own language where possible in order to remain close to their accounts and preserve nuance across individual experiences rather than being drawn into the researcher's own assumptions and experiences when data was generated. Reflexivity was particularly important given personal and professional proximity to the topic to reflect on what in the data she was drawn to and why e.g., was it because it appeared as a strong pattern across accounts or because it was personally salient to her?

Supervision, consultation with PPE and discussion with a research apprentice was utilised to enhance insight on data generation and theme development as recommended by RTA guidelines in best practice (Braun & Clarke, 2024). This ensured the analysis remained close to participants accounts while also recognising that as a researcher she was an analytic tool and the aim was not to produce an 'objective' analysis. For example, the data generated relating to the awareness of under resourced services were within the participants accounts and not solely brought by her experience of working in under resourced health services. Additionally, reflection on her belief that death remains socially taboo may have heightened attention to participants' accounts of needing spaces where difficult conversations could occur openly. Showing curiosity around this enabled the questioning of whether this was a theme or was a lesser factor in the dataset. However, this was balanced with holding the notion that in RTA the researcher is always shaping their research, therefore it will always be infused with their subjectivity and they are never a neutral deliverer of an objective truth of participants' experience (Braun & Clarke, 2023). Furthermore, M.D-E chose not to disclose her previous experience in these settings to participants, out of concern that doing so might influence their accounts. In retrospect, however, she reflected that social constraints around discussing death and dying may have contributed to this decision.

Conclusions

This project provided a nuanced account of patients' and carers' experiences of formal psychological support in palliative care. Enablers to accessing formal psychological support was a holistic, hospice wide environment that provided psychological safety and practical support to lessen concerns e.g., a step back from caregiving roles for carers and the management of pain and illness for patients. A further enabler was the perception of hospice resource as finite, which led participants to accept support with gratitude for receiving it. However, gratitude also functioned as a barrier to asking for additional or adapted support as they perceived that this would not be available. Further barriers may involve a lack of safety by the whole hospice system, which may limit the willingness to access and share openly in formal psychological support. It highlights the complex process and overlapping patterns by which psychological support is beneficial for individuals during a significant time of life. Individuals are shaped by socially constructed expectations regarding the duration and course of life events. However, a life limiting diagnosis brings a stark realisation that this is not the case and instead there is an emphasis placed on the immediacy of the present moment, highlighting the importance of engaging fully with one's surroundings and relationships. Consequently, recalibrating the lens through which expectations of oneself and others in the context of life and loss are understood is essential. Within contexts characterised by enduring uncertainty, including hospice care, such reframing supports a focus on present-moment awareness, relational connection, and the meaningful utilisation of life remaining (Reneau & Eanes, 2022).

Declarations

Ethics approval and consent to participate

This research was performed in accordance with relevant guidelines and regulations such as the British Psychological Society's Code of Ethics and Conduct (2021). Ethics approval was granted by a Research Ethics Committee at the University of Bath (7287-20289). Through consultation with an officer at the National Institute for Health Research (NIHR), NHS ethical approval was not needed as hospice patients were not NHS-funded. Additionally, The Bath, Northeast Somerset, Swindon, and Wiltshire (BSW) Research Hub approved the project to recruit from Dorothy House Hospice and confirmed that NHS ethical approval was not needed. Furthermore, the main researcher (MD-E) followed each of the individual hospice's ethical approval process which was unique to each hospice. All participants provided informed consent prior to participation.

Consent for publication

Consent for publication was not required.

Availability of data and materials

Anonymised datasets and study materials can be made available from the corresponding author on request.

Competing interests

The authors declare that they have no competing interests.

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Author's contributions

MD-E conceived and designed the study, collected and analysed the data, and wrote the manuscript. RE provided supervision and methodological guidance, and critically reviewed the manuscript.

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Author's information

Maria Davies-Edwards is a Trainee Clinical Psychologist at the University of Bath.

Dr Rachel Evans is a Senior Lecturer at the University of Bath

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Figures

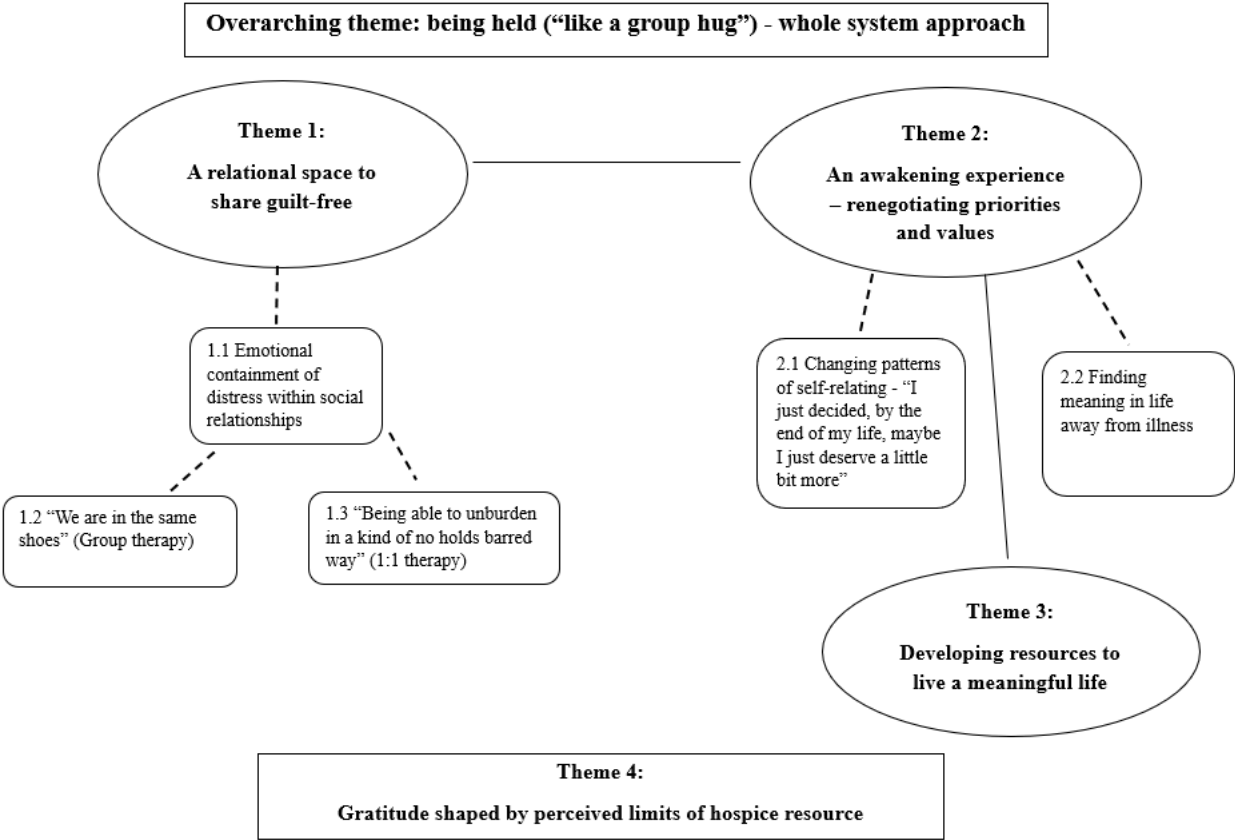


Figure 1
Thematic map

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