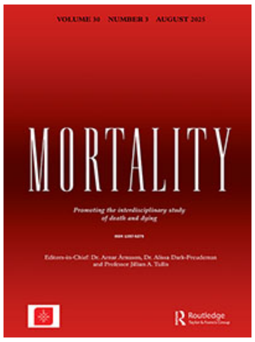

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‘Maybe I’ve got lost in the system somewhere’ patient experiences of palliative care: a case study of Frances

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ABSTRACT
Palliative care is a complex process of managing holistic care and support needs at a crucial point in a patient’s life. Statistics show many people are not accessing appropriate care when most in need. This case study of one terminally ill cancer patient, Frances, enables an in-depth exploration of the experience of palliative care. This adds a unique perspective to the current research on end-of-life care. Using this novel approach, we aim to increase understanding of palliative care, of ‘being in the system’, through a patient’s lifeworld. Through this lens of Frances, we can learn about the struggles of navigating care, families, friendships and societies, highlighting valuable lessons for those involved in palliative care. Key findings are that the humanistic and emotional support needs of a patient approaching end-of-life were not perceived to be addressed, causing psychological and physical impact. The lack of understanding and awareness of a patient’s emotional experiences at end-of-life impacted on provision of appropriate care and support. Individual perceptions and knowledge of palliative care options also created barriers in applying and accepting non-medical support when needed. This has implications for developing approaches to improve access and quality of care.

KEYWORDS
Palliative care; cancer; relationships; humanising care; lifeworld

Introduction

Palliative care is defined by the World Health Organisation as care focussing on the medical, physical, psychological and spiritual needs of patients with incurable medication conditions and approaching end-of-life (WHO, 2020) which is often considered to be the last 12 months (National Institute for Health and Care Excellence NICE [NICE], 2019). An estimated 14% of people who may benefit from this holistic care worldwide receive it (WHO, 2020). Globally, access to palliative care is also known to be inequitable, despite efforts worldwide to improve access and inclusion (Koffman et al., 2023; Stajduhar & Gott, 2023). There have been focused movements to bring provision more into a public health and community-based model of care (Kellehear, 2019) however research still shows varied and unequal access to care at end-of-life (Bulle et al., 2023; Moore et al., 2024)

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Research into patient experiences is helping to improve palliative care, for example through development of more informed outcome measures (McCaffrey et al., 2024), highlighting the need for regular assessments into quality of life (O'Connor & Pesut, 2024) and training for practitioners in communication with patients at end-of-life (Chapman et al., 2024; Kitta et al., 2021). This increase is in line with recommendations for research to move towards community-based studies which are centred on patient voices and lived experiences (Stajduhar & Gott, 2023). Individual case studies can provide comprehensive explorations of complex phenomena in a real-life setting (Yin, 2009) and highlight potential gaps or issues within health service delivery (Paparini et al., 2020). Indeed, case studies are used within practice to better understand patients, to consider service improvements (Abma & Stake, 2014), and so that practitioners 'can extrapolate from the findings of the skills, knowledge, and values/attitudes in relation to the care their routinely provide' (Read & Cartlidge, 2012, p. 27).

Understanding patient awareness of their condition, their prognosis, and the choices available for care, but also about the assumptions that are made by professionals about what information should be provided to them, is crucial to care provision (Glaser & Strauss, 1965). Research has evidenced that both patients and the general public can have a low level of knowledge and be misinformed around palliative care (Atena et al., 2022; Diviani et al., 2023; McClouth et al., 2023). Research focusing on improving knowledge of care services at end-of-life has shown significant numbers of missed referrals into care provision for eligible patients (Knowles et al., 2024), with the fragmentation of care involving multiple practitioners exacerbating misinformation and poor knowledge of patients (Stacey et al., 2019). Research into patient experience has evidenced unmet needs including management of physical symptoms, emotional support, and care for social wellbeing – with acknowledgement that firsthand knowledge is required from patients to effect changes in palliative care services (López-Salas et al., 2024). This paper suggests that unmet needs experienced by patients at end-of-life can be viewed within the lifeworld approach where the focus is on the humanising and dehumanising concepts of care.

The lifeworld approach derives from Husserlian philosophy which, within a care context, considers the humanising and dehumanising elements of care interactions and systems (Todres et al., 2009). The lifeworld helps to explain a person's relationship within their world including their interpretation of culture, sensations, and making sense of their experiences (Shaw et al., 2023). It comprises key elements including 1) Emotional Attunement – seeing the inner person and what makes them 'tick', 2) Intersubjectivity – belonging and interpersonal connections, 3) Temporality – how time and continuity are experienced, 4) Spatiality – to feel more 'at home' or close to our environment, and 5) Embodiment – the person beyond the diagnosis, living meaningfully. Lifeworld can be effective in collecting and analysing qualitative data relating to existential concepts such as end-of-life (Åberg et al., 2020; Palmér et al., 2020) and have been used to help explore people's personal in-depth experiences around their health and care (Ee et al., 2024; Jonassen et al., 2019).

This paper adds to current debates around palliative care, by presenting the in-depth experiences of one patient who felt 'lost in the system'. Recognising and addressing a patient's lifeworld enables a unique voice to be included into conversations around accessing and inclusion within health care at end-of-life. Through

Frances, we advocate for the use of humanistic care to see the individual beyond the patient and understand their world. Frances was a participant within a larger study researching perspectives and experiences of hospice care. That original study is explained next.

Original study

This case study is taken from the participants of a larger study investigating the perceptions of hospice care within one geographical community. Hospice care is known to be inequitable (Tobin et al., 2022); however, there has been little research undertaken to evidence people's perceptions of hospice care, who is eligible, and how to access care. This study was unique in that it sought to uncover those perceptions from one geographical region and incorporate multiple voices from different communities and backgrounds, including professionals, patients, and the public. Frances was a patient who was known to be in the last months of life but was not accessing any support from hospice services, or other organisations at the time of interview. The original study included 8 patients, 33 professionals working with people who may have life-limiting conditions, and 15 members of the general public.

Recruitment

Recruitment was undertaken through the National Health Service (NHS) within a specific region of the UK. Palliative care practitioners within the hospital and local hospice were asked to identify patients who were over 18, had a good understanding of English, were considered psychologically and physically able to participate, and in the last year of expected life. This is a common identifier within palliative care which is embedded in the Gold Standards Framework Prognostic Indicator Guidance (Thomas & Wilson, 2022) and is often used by professionals when assessing need; it is referred to as the 'surprise' question, that is, would a professional be surprised if the patient died within 12 months (Downar et al., 2017). Those patients who fitted these criteria were given study information by the practitioner and asked to contact the researcher directly if they wished to participate. The patients were aware of their prognosis; the eligibility criteria were part of the study information given to participants prior to consent and interviews. Interviews took place throughout 2018–2019.

Interview process

An in-person interview was undertaken within the patient's home and followed a semi-structured approach. Meeting with Frances enabled her to tell her 'story', expressing her identity, feelings, reactions, and perceptions of her illness, care, and treatment, including areas where she did not feel supported, and how it impacted on her emotionally. All participants were asked open-ended questions about care when approaching end-of-life, and their perceptions of the terms 'hospice care' and 'palliative care'. This included probing around eligibility for care, types of care, and how to access care.

Ethical considerations

Ethical approval was gained from the Open University on 1 March 2018 ref HREC/2768/Saunders, and the UK National Health Service Research Ethics Committee (NHS-REC) on 16 May 2018 ref 18/LO/0525. Participants were provided with information sheets and were also provided with support after involvement, when necessary, for example, signposting to relevant support services. In this paper, data have been anonymised to protect patient confidentiality, and the names have been changed to prevent identification of those who took part. Careful consideration has also been given to all potentially identifying pieces of information about the patient's life circumstances and health situation.

The case 'Frances'

Frances was a 47 yr old white British woman with a history of cancer for 12 years before she died. She was married with one adult son from a previous relationship. Frances was from a middle-class background and lived in an urban area within a large town in the south-east of the UK. She was not accessing any palliative care services at the time of the interview, apart from attending appointments for symptom control within the hospital setting. Frances did not appear to be fully aware of all possible support and resources locally, or her eligibility, for example to access the local hospice provider. A brief timeline of those 12 years is given below in Table 1. Name and dates have been altered for anonymity.

Frances was informed of the study by a palliative care consultant within her local hospital and was interviewed in person as part of the original study. Frances' case is presented here due to her diagnosis of cancer – a common life-limiting condition within UK which is the primary condition seen in patients receiving hospice care and her socio-economic and ethnic background – we know that palliative care access is often biased towards this demographic (Tobin et al., 2022). Despite this, Frances still experienced specific issues and challenges in receiving appropriate care. Her insight into those challenges is shown through her frank and open responses recalling her care experiences during the interview, which was conducted in her own home for over 90 minutes.

Table 1. Timeline.

2007	Married.
2008	Diagnosed with breast cancer stage 3. Emergency treatment. Lumpectomy, mastectomy on one breast, chemotherapy, radiotherapy. Medications.
2011	Diagnosed again with breast cancer. Chemotherapy, radiotherapy, stomach implants. Hair loss. 6 months later still present. Mastectomy on other breast. Advised now 'palliative'. New medications. Declined further chemotherapy due to quality of life.
2014	Cancer detected in various locations including skin. Stopped full time work. Pain increasing and quality of life reducing. Electro chemotherapy. Repeat infections from open wounds. Hospitalisation 3–4 times per year.
2019	Declined offer of clinical trial. 3 monthly oncologist and CT scans, 3 weekly Symptom management appointments. Frequent hospitalisation from infections/pain. Attended lymphedema clinic. Accepted invite to participate in this research project. Interviewed.
2020	Died.

Case study analysis

The analysis of the interview with Frances adopted an inductive and reflexive thematic analysis (Braun & Clarke, 2024). This involved immersion in the data by the first author, through repeated reading, a period of open coding, followed by creating themes (Terry & Hayfield, 2020). The second author provided support with ensuring validity and reduction of bias within generated themes (Nowell et al., 2017). During the analysis, the lifeworld approach was used as a framework for the themes to enable a focused exploration and organisation of the data focusing on Frances' experiences. An ecomap was also produced from the data and information given by Frances. Ecomaps visualise the complex key spheres of a patient's life including their relationships and flow of certain resources such as support (Hartman, 1978) and can be particularly useful when exploring case studies around positive and negative experiences of health care (Kruger et al., 2024). This was chosen to help visually understand and represent not only the relationships connected to Frances' care and her lifeworld but also the quality of those relationships (Manja et al., 2021).

The ecomap of Frances' lifeworld and support

The ecomap shown in Figure 1 highlights the support Frances received. This included the hospital which was solely concerned with her medical treatment and which she perceived did not consider her emotional, psychological and social needs. From her perspective, she felt she was not receiving care from her family and was not able to request this (though she perceived she had some support), and she was disconnected from significant external and regional support systems such as her local hospice, charities and community. Frances' account differentiated her friends into four groupings; those who supported her compassionately with an understanding of the reality of her prognosis and the anticipated grief experienced, those who provided emotional support, those who helped her with strength to practically manage her prognosis, symptoms and treatment, and those friends she referred to as 'lost' who had stopped interacting with her as she became ill. The only other support that Frances acknowledged and appreciated was from her pets, who provided her with comfort, companionship, and some quality of life through taking care of them and going for walks etc.

Findings

The lifeworld approach

During the interview, Frances recalled aspects of her life connected to her care, treatment, and quality of life primarily in relation to her social and psychological well-being. These recollections resulted in emergent codes which were analysed using the lifeworld constituent components. Frances' experiences and perceptions of her treatment, care, and support are discussed through the lens of each of the lifeworld dimensions in turn, focusing on what that means for practice and future research.

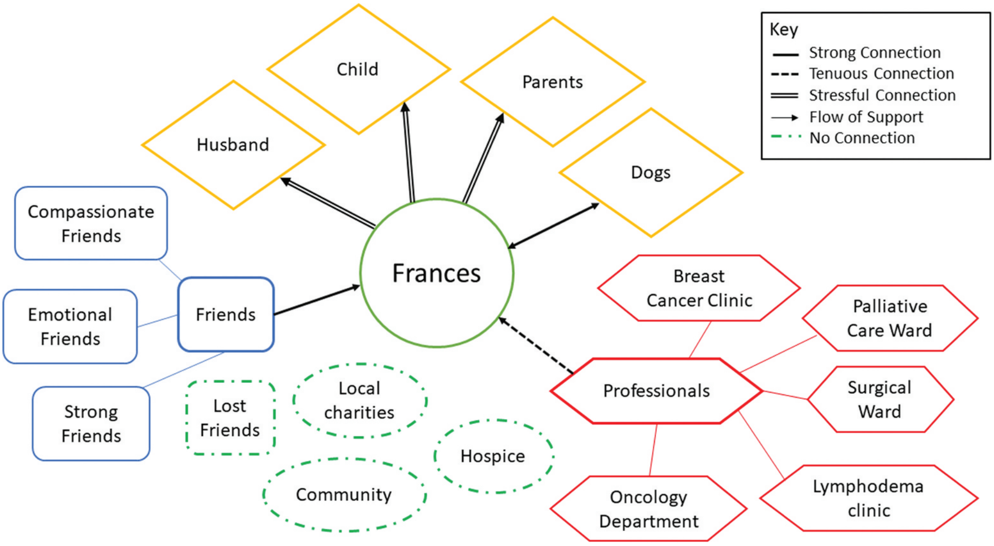

Figure 1. Frances Ecomap.

Emotional attunement

> I was really upset and I shouted at her, but it was because I was worried and cross and everything.

Emotional attunement is how our emotional state influences our world and decision-making both positively and negatively (Galvin et al., 2020). Understanding someone's emotional state is an important part of knowing their lifeworld and enables rapport building and creation of a supportive clinical relationship. The quote above was an example of an interaction Frances' recalled with a cancer specialist nurse where she recalled an emotional response during a difficult appointment. Compassion is defined as having a relational understanding of someone's suffering, albeit a phrase often confused by patients with empathy and sympathy (Sinclair et al., 2017). Frances commented *'There is quite a shortage in compassion there'* when discussing her experiences within the hospital and perceived it to affect the care and treatment she was offered.

> I don't really cry in front of people, unless I'm ill, and you know when you are feeling ill and you feel down and you just want to be babied anyway, that's when I want to talk more about things.

Frances perceived that her condition and symptoms were part of her being and being denied opportunities to express her own feelings about her situation with both professionals and her family, exacerbated her stress and depression. Frances showed emotional vulnerability through crying as her way of indicating she wanted support. The lack of opportunity to talk things over impacted not only on France's physical health as she recalled that it caused her to decline treatments but also impacted on her emotionally; she became verbally aggressive and experienced clinical depression.

When delivering care, it is crucial for clinicians to not only be aware of the emotive nature of that care and treatment but also how that can affect patient's behaviours, communication, decision-making, and mental health, even in-between appointments as Frances recalled:

> In-between scans I'm waiting for the cancer to hit, you know, like liver, lungs, brain … so every time I go for one of these scans it is like a real ffffff horrible moment.

The emotional impact on Frances of ongoing cycles of symptom management and scans created anxiety, fear, and depression, all of which she expressed needed support at times, but did not perceive her emotional state was recognised and acknowledged, including how that influenced her needs and responses to care.

Intersubjectivity

> I have friends that I would talk to if I want to cry. I've got friends that I would talk to if I just want to rant, and then I've got a friend who is like "Oh for God's sake its" only cancer!' when you need that kind of friend.

The intersubjectivity of the lifeworld approach allows consideration of connections with others in the world including friends, peers, professionals, family, and the wider society. Interactions with others may be varied due to the overwhelming emotive nature of supporting someone who is approaching end-of-life (Lung et al., 2022).

Frances acknowledged she had friends who supported her in different aspects of her life, but she found it challenging to connect with her parents and husband, because of their reluctance to be open about her prognosis, and the emotional weight it placed on them, which can create feelings of being a burden (Liu et al., 2022). Frances also noted how others or distanced themselves.

> It's funny how many erm, friends you lose, or I say friends, but you know acquaintances you lose because they don't know how to say anything.

Frances was not aware of any cancer patients with terminal diagnoses that she could connect with. Frances perceived patients with cancer as being either depressing or displaying a pride and 'bravery' (Taubert, 2016). She believed she could not relate or connect to other patients because they were not like her.

> I either met people that are so depressing that you just want to get your rope out now because they are all doom and gloom … And then I haven't got time for the ones that want to kind of boast about what they've been through, it's almost like (laughs) … You know, 'hey look at me! I've kicked cancer's ass!' I hate all of that shit … .

Poor professional interactions, particularly with multiple transient staff, can hinder the development of meaningful relationships (Rehner et al., 2021). Interaction with professionals in Frances' lifeworld appeared to her as dehumanising, exacerbated by a lack of staff continuity, causing her to feel *'lost in the system'*.

> I saw some head of oncology nurse that I'd never met in my life, and an oncologist who I'd never met before, and I was saying to them 'I'm in real pain here' … and they were like, they did all the nodding and blah blah blah and went away and nothing happened.

One strategy to help with continuity could be providing a care coordinator, which may be referred to as a patient navigator or keyworker. This was proposed by Frances and is known to be effective in improving high-quality palliative care (Feuz, 2014):

> It would be nice to know you have a key person, because . . . everything would worry me, like the slightest backache would worry me, and there was, and I never felt like there was anyone I could check with those things, you know, who do you go to, well you kind of don't, you wait until something else pops up.

Frances acknowledged in the interview that she was not aware of how to access any other support options within her community and did not know what different services were available:

> I was never offered [hospice]. . . In fact I thought you just went there to die, like my aunt had done and whatever . . . So I didn't realise you could have help from them. Also, I've never had, never been offered help from Macmillan like in the thingy, you have a nurse. I've seen the nurse, she kind of walks down, shuts the door and that's it. I've never been offered a chat, or whatever.

The lack of interaction and human contact with other services created a sense of distance for Frances, where she perceived she could not access any help for her holistic and humanistic needs during her illness. Crucially, having the knowledge about other possible sources of support could have alleviated some of Frances' emotional and psychological distress, by enabling her to connect with other patients, connect with practitioners, and support to connect with her family.

Temporality

> When I was in hospital this time, they were saying it would be good if I came up every couple of days and have the wounds cleaned. I was like 'Absolutely not, you are not stealing every other day off me.

The temporal element of the lifeworld approach considers how time is experienced and affects us within our worlds. For Frances, this was evident in her discussion of managing the time spent on her treatments.

> I got cellulitis, but they thought it was sepsis because they were ringing me at home telling me to go in, I was asleep so I didn't hear it, and then they were like 'oh we need you to call us straight away' but I hadn't had breakfast and the dogs hadn't had a walk, so I did all that first (laughs) and then I went in.

She recalled difficulty in balancing having an authentic and meaningful life alongside her treatment participation (Plage & Kirby, 2022). Frances' dislike of appointments, particularly those which took place in the hospital, has been highlighted by others as an issue for patients who report it can increase their awareness of the ambiguity of living and dying (Lowrie et al., 2019). Time spent at home or with family and friends can be seen as living, whereas having to spend considerable time at clinics, onwards, receiving medical care can cause an enhanced realisation of dying. This caused disagreements between Frances and her relatives around deciding whether to use her limited time for treatments as opposed to time spent with her family or leisure interests.

> My husband was like ‘well I think you should go’ and you know ‘I think it would be really good’ and I said ‘but it’s not your life’ and in between my chemo visits I try and forget about the hospital, there is no way in this earth I am going up there every other day to get a wound cleaned.

For Frances, having the flexibility to have appointments at home rather than going to the hospital was a clear strategy that supported her needs and enabled her to feel more in control of not only her time but her care environment.

Spatiality

> the nurse came to my home, probably spent maybe half an hour and it was nice, didn’t feel like I’d been in hospital, just felt like I’d had a visitor.

Environment and space are highly influential for patients and carers. Options for care outside of the traditional medical spaces may help people at end-of-life who are conscious of their limited time and value that time spent within their home or other preferred place. Facilitating such options could be challenging due to the financial and staffing implications that may arise, however, as Frances recounted, the difficulty of attending, and frequency of appointments for patients at end-of-life can lead to non-compliance, creating potential future complications with treatments and care (Paiva et al., 2020). Non-compliance was Frances’ reaction to her multitude of hospital-based appointments, and such responses could impact negatively on prognosis.

Frances expressed how she prioritised walking with her dog, not just because of the use of time as explored earlier, but also because she found walking in nature beneficial, and a preferred place for her to spend time rather than in medical buildings. This connection to a natural environment was important to Frances for her relationship with her son as they used that time and space to connect emotionally and provide support for each other.

> We’ll go through [park name] or through the woods and stuff and I know then that he wants to talk and so he’ll talk and inevitably we’ll both get upset and have a good cry, and then it’s kind of over and done with until the next time.

Frances was not aware of any other places for support, beyond those she used regularly – her local area for nature walks and her home environment. She wasn’t connected to other places which could help her, such as social spaces, hospices, or community support groups.

Embodiment

> I think losing that (hair) and my eyelashes, once my eyelashes went that was awful,because then I looked ill, I looked like I had cancer, and I didn’t want people to feel sorry for me.

Embodiment, in terms of the lifeworld approach, considers how our physical bodies relate to our own lifeworld. As Frances noted, ‘it’s not just about getting the right meds and scans and things’. The interview with Frances showed difficulties with how she perceived herself, and how she was perceived by others, which caused emotional stress and impacted on her ability to connect with others. She did not want to be labelled as sick or dying, but equally she did not want people to dismiss her condition, her symptoms, and the reality of her prognosis.

One concern is having to accept and manage the changes not just in physical appearance which the condition or the symptom management treatments can cause, but also the non-visible reality of dying that can impact on relationships with others. Frances recalled that she did not present visually as a 'typical' cancer patient or as dying:

> I think people just think you take chemo, your hair falls out, you're sick, you look yellow (. . .) and cos I don't look like that. But I tell you what, it's one of the most annoying phrases in the world when people go 'God you look so well' you just think AARGH! you almost want to carry your scan pictures around with you, or lift your top up and go, 'Check this out!'.

Frances wanted to be acknowledged as having cancer, and in her last months of life, but without the physical signs in her lifeworld, this made it difficult. She perceived she wasn't being accepted as who she really was – a person who was dying.

In contrast, physical manifestations of dying can cause a labelling of patients. This can cause an emotional response as Frances noted when she first discovered she was labelled as 'palliative'.

> I heard the first word, like the care would be palliative. And I said, 'what do you mean palliative?' and she said 'oh, because there is no cure, we are not curing you now, we are just extending your life'. And that was the first time I had ever heard it, so I burst into tears, and she was really apologetic, she thought I knew this, and I said 'no!'

Frances was aware of how other patients responded to their prognosis and label of dying, as mentioned earlier in the form of 'giving up' or 'fighting'. However, Frances did not perceive herself as fitting either of those labels, but rather her embodiment was perceived as her being uniquely herself, Frances. She expressed a desire to be accepted as who she was, which included an acceptance of her condition, her symptoms and her physical manifestations of her illness. For Frances, that was her embodiment, and she expressed frustration that it was not always acknowledged by those around her, and when it was, the responses of people 'feeling sorry' were not helpful and contrary to what she perceived she needed.

Discussion

Understanding Frances, the woman, the cancer patient, the mother, the daughter, the friend, was crucial to Frances in providing the care and support that she perceived she needed to manage her deteriorating condition. In this discussion, the focus will be on how this impacted on her interactions and how this understanding might be used to improve end-of-life care.

Humanising care through connectivity with practitioners

The experiences of Frances have evidenced the need for practitioners to acknowledge and respond to their patients' lifeworld to provide holistic and humanistic care, meeting the emotional needs of patient as well as the medical. Indeed, Frances highlighted that it could impact on receiving medical care, as patients' may be less likely to want to comply with appointments and treatments. To better support people like Frances, it may be that a greater consideration is required by professionals of how patients value their own time, and acknowledgement of the difficulties of managing living while also managing the treatment required for a body that is dying. Timing appointments sensitively or offering virtual options (Castro et al., 2024) may help to alleviate some of the stress for patients, but even just acknowledging how intrusive appointments can be for patients, may help to improve the patient – practitioner relationship. Having greater flexibility could be achieved if more care services worked together to create what Hui et al. (2023, p. 1) described as 'care anywhere, anytime'. For example, the use of natural space such as parks and gardens in providing opportunities for connecting with others, and the support that comes with it at end-of-life could be a consideration for patients as a means for holistic care, addressing physical, emotional and psychological needs (Al-Abdin et al., 2021).

For palliative care practitioners to be more attended to their patients' lifeworld and needs may be emotive (Hubik et al., 2021) could require specific training and support from mental health colleagues, particularly as it has been hypothesised that not all non-physical suffering in palliative care can be alleviated (Rattner, 2019). Research also suggests that palliative care practitioners may lack confidence in their knowledge of mental health, and there is a need for greater connectivity between palliative care and mental health services (Park et al., 2022).

Palliative care services could also consider using more specific outcome tools to measure the effectiveness of interventions (Dodd et al., 2020), which could consider not just the holistic nature of care at end-of-life, but also the lifeworld of patients and how their perceptions and needs could be accommodated within a service model delivery, covering areas such as social relationships, independence, environment and psychological needs (McCaffrey et al., 2024). Introducing care coordinator provision as Frances suggested could also be another way to support patients in accessing appropriate care and support which fits into their lifeworld rather than imposing upon it. Care coordinators are used within general health care but have not been widely implemented for palliative care (Budde et al., 2022). In the UK, there are national guidelines advocating the need for care coordination for patients approaching end-of-life, but it does not stipulate whose responsibility that would be within the health team, or whether it would be a designated role (NICE, 2019).

Supporting interpersonal relationships

Humanising care from family and friends was also identified as important to Frances in this study. Receiving emotional and practical support from friends and family has been identified as essential for patients to help feel safe, prepared and supported across their trajectory (Marshall et al., 2024), and was valued by Frances from her friendship network. Frances was receiving some support from her network of friends. Peer support when approaching end-of-life can often help provide emotional support (Rutkowski et al., 2018); however, Frances demonstrated that this can be difficult. For some, hiding symptoms and physical decline can be a way of avoiding burdening others (Moyse, 2021) and to distance from the label of 'dying'. However, Frances commented, she also wanted people to acknowledge that she was dying, as this was an intrinsic part of who she was, even though such labelling can be a form of dehumanisation (Elton, 2022).

Garnering support from family can be difficult, especially when faced with the juxtaposition of needing to provide care for them (Arantzamendi et al., 2020) and managing their own anticipatory grief and loss. Family carers need external support (Tieman et al., 2023), which had not been offered to Frances' family. This could not only have strengthened them to acknowledge and manage the emotional trauma of her prognosis but also informed and equipped them to help meet her changing needs. For example, Frances valued her quality of life over treatments which had debilitating side effects, however her family were still keen for her to pursue medical interventions. Having support to understand a family member's choices around their care based on their lifeworld could therefore be invaluable for families coming to terms with a loved ones' prognosis and their preferences.

Peer support when approaching end-of-life can often help provide emotional support, empathy and a sense of 'normality' of life (Rutkowski et al., 2018), which may include people with similar medical conditions and prognoses. Connecting like-minded patients to gain mutual support through a shared connection has been reported to help improve quality of life (Tan et al., 2023). This could be supported by health practitioners through interactions within health care settings, and through the wider communities and social networks. Frances' perceptions of other patients receiving palliative care as 'martyrs' was preventing her from pursuing this as a potential solution for supporting her social and emotional needs.

Frances' case has highlighted the potential need of patients approaching end of life to create and maintain relationships in an environment which is rapidly shifting, and which can be difficult to discuss openly, particularly with family and friends. The concept of death and dying being a taboo subject within societies has been challenged in recent years (Brennan, 2022), but patients like Frances are still experiencing difficulties socially in not being heard or understood. In the UK, national campaigns such as 'Dying Matters' and the 'Compassionate Communities' social movement are illustrations of the wider acknowledgement that these issues need to change. The aim of these movements is to empower local populations to be accepting of death and dying and empowered to provide appropriate support and care, improving outcomes for people at end-of-life (Aoun et al., 2023). However, palliative care and the lives of those who are actively dying are still not fully understood within society, for example where hospices are still perceived wrongly as only being places for people to die (Bayley, 2022).

Implications for palliative care

This paper used a lifeworld approach to explore in-depth how Frances was experiencing her last months of life not just physically, but also connecting into how she experienced her environment, her time, and her interactions with others (van Manen M, 1990). It has allowed the complexities of palliative care and support to be explored through Frances' representation of a person at end-of-life. More widely though, seeing people as human, especially when they are actively living but also aware that they are actively dying, is crucial to moving towards an acceptance of people who are dying within societies. For anyone involved in providing care and support for people with life-limiting illness, it suggests the need for delivering a form of lifeworld-care (Pryce & Shaw, 2019), focusing not only on the holistic aspects of care associated with palliative and hospice care but on the personal

Table 2. Implications for care provision.

See the Human Behind the Condition	Acknowledge a patient's lifeworld and its impact on their emotional and psychological lives, and care needs
Continuity of Care	Consider care coordinator for identified palliative patients to improve communication, continuity of care, and access to relevant services and support. This could also help support health literacy around death and dying, and care options
Improve Connection between Patients for Peer Support	Palliative care providers and primary health settings could support patients developing support networks within communities locally and online
Recognition of Value of Patients' Time	Especially when arranging and facilitating appointments. Consideration of reducing frequency or combining different appointments, and acknowledging the psychological ambiguity of patients both living *and* dying
Use of Appropriate Outcome Measures to Improve Humanistic Care	Use of outcome measures or other evaluation tools which are more aligned to the patients' lifeworld may help to better identify good practice and areas for improvement
Acceptance of the Importance of Home and Other Spaces	Thinking beyond the hospital and hospice to other environments as a place of care, and encouragement of choices of preferred locations
Identifying and Targeting Families for Support	Healthcare shouldn't just be for the patient. Consider wider support for families and friends, to reduce the perceived burden of care experienced by patients
Societal and Institutional Change to Reduce Stigma	This includes the normalisation of death and dying, and the stigma around the concepts of palliative and hospice care. UK and worldwide initiates such as Death Cafes, and Compassionate Communities are examples of successful initiatives

experiences of patients and how they interpret their individual worlds. This will also help to identify and attend to the patient's existential experience Tarbi et al. (2024).

This case study of one patient has sought to expose the need to move away from the focus on disease and treating symptoms, and towards the patient's perspective of their care and support requirements. Humanistic palliative care is gradually being seen in practice, and while there can be barriers, there is evidence of its effectiveness, and guidance for enabling greater understanding of patient experiences, and their lifeworld (Liang et al., 2024; Skorpen Tarberg et al., 2020)

From Frances' experiences, there are some key considerations for those providing care for people in the last months of life, which are summarised in Table 2 below.

Strengths and limitations

This paper represents the views of one patient experiencing her own distinctive life journey, and as such is therefore limited in what it can say about perceptions of hospice care and how they impact on access and eligibility.

A single case study however is a strength as it provides in-depth evidence which is not always available through a larger study with multiple participants. By adopting a case study using a Lifeworld approach, a clear understanding of one patient's perspective and experiences was fully explored. This article therefore demonstrates the range of challenges faced by Frances as well as drawing attention to her specific needs.

We were able to explore in detail the circumstances, challenges and needs within palliative care, from the perspective of one patient living and experiencing first-hand the challenges of receiving appropriate care when dying. Further investigation into other patients who are not accessing appropriate palliative care would help to build knowledge on this perspective, particularly those from outside the UK. It would also be helpful to include diagnoses that are non-malignant, and patients from non-white, deprived backgrounds as this may well expose more of the challenges in accessing and receiving appropriate personalised care when approaching end-of-life.

Conclusion

This case report identifies key concerns when focusing on accessing appropriate palliative care and support when approaching end of life. It is crucial that the person behind the patient is seen; following a humanising approach to care and being cognisant of the patient's own lifeworld can assist this. It needs a greater collaborative and supportive professional environment, where holistic services are encouraged and offered to all patients and their families/carers. It needs support for patients in navigating the complex care system, so they can be more aware of potential support networks including non-medical, informal settings and with peers. Finally, greater action is required on changing the social culture around death and dying, to make dying not only more visible but also normalised within societies, so the label of dying receives responses and reactions which are supportive and understanding, in line with people's needs and wishes when they are approaching end-of-life.

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Ethical statement

The Ethics Review Committee at The Open University approved our interviews (approval: HREC/2768/Saunders) on 1 March 2018Y. Respondents gave written consent for review and signature before starting interview.

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