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Patient and family members' experiences with language and environment when receiving bad news: A qualitative exploratory study

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Abstract

Objectives. Receiving bad news about one's health can be devastating, yet little is known about how the therapeutic nature of the environment where bad news is delivered affects the experience. The current study aimed to explore how patients and their families were affected by the language and the built, natural, social, and symbolic environments when receiving bad news, through the Therapeutic Landscapes theoretical framework.
Methods. Patients diagnosed with a life-limiting illness living in regional Victoria who had a hospital admission within 24 months and a diagnostic/prognostic conversation were invited to participate, as well as a family member who witnessed the conversation. Participants were recruited through social media and snowballing, resulting in 14 online semi-structured interviews being conducted between November 2021 and March 2022, audio-recorded, and transcribed verbatim. Reflexive thematic analysis was used to develop the themes.
Results. Fourteen semi-structured interviews were conducted with women aged between 30 and 77 years. Interviews lasted between 45 and 120 minutes, with an average of 69 minutes, and were conducted online or via mobile phone. Four central themes were developed: "Hearing bad news for the first time," "Preferences for having hard conversations," "Creating a sense of safety for ongoing care," and "The therapeutic nature of the ward."
Significance of results. This body of work will help inform practice and future policy regarding bad news delivery and the design and aesthetics of environments where bad news is delivered. It is essential that bad news is delivered within a quiet, calm, and emotionally safe environment within a supportive therapeutic relationship.

Introduction

Receiving bad news regarding a serious chronic disease or diagnosis is life-altering for patients and their family members (Miller et al. 2022a). Research abounds with guidelines and protocols aiming to aid health practitioners in effectively communicating bad news in ways that support the recipient and provide a supportive experience (Baile et al. 2000; Berkey et al. 2018; Narayanan et al. 2010; Rabow and McPhee 1999), but there is still room for improvement. Often bad news is delivered by the patient's general practitioner (GP) within a familiar environment and where therapeutic relationships have already been established, enabling a smoother bad news delivery process (Berkey et al. 2018). At other times, bad news is delivered in the hospital by generalist medical practitioners or specialists who have had no prior relationship with the patient and need to quickly assess the patient's readiness to receive bad news (Anderson et al. 2013). Regardless of the relationship, bad news needs to be delivered incrementally and circularly with enough time for questions (Bousquet et al. 2015; Miller et al. 2022a).

Although therapeutic relationships with health professionals may contribute to a positive experience in the delivery of bad news, little is known about whether the therapeutics of the environment where this conversation takes place contributes to the understanding of receiving bad news. Patients with life-limiting illnesses receive care and treatment within the same hospital environment as acute patients, yet they have different needs (Miller et al. 2022b). The focus of an acute medical ward is to prolong life within a fast-paced, task-focused culture with little priority for psychosocial care (Chan et al. 2018). In contrast, patients with palliative needs prefer a deinstitutionalized environment (Rasmussen and Edvardsson (2007) and a more relational cultural milieu (Robinson et al. 2018) with a slower pace and space for family (Sekse et al. 2018).

The theoretical framework of "Therapeutic Landscapes," coined by Gesler in 1992, highlights the relationship among people, health, and place (Andrews 2002) through understanding how "physical (natural) and built environments, social conditions and human perceptions (symbolism) combine to produce an atmosphere which is conducive to healing" (Gesler 1996, p. 96).

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Further, the 4 environments need to contain a belief in the healing power of nature; a feeling of a sense of trust and security in what the built environment represents; an understanding of the meanings that are held within symbols and rituals; and a social environment that provides equality, community, and support (Gesler 2003). "Healing is multidimensional and includes physical, mental, spiritual, emotional and social elements" (Gesler 2003, 3), making it relevant for people with palliative and end-of-life needs (World Health Organisation (WHO) 2020).

In recent decades, capital works have improved the aesthetics of hospitals as therapeutic places by introducing nature (gardens and views of nature) (Weerasuriya et al. 2019) and improving building design and ambiance (Gesler 2003; Schreuder et al. 2016). Hospitals are laden with symbolism and rituals that evoke different reactions in people (Rasmussen and Edvardsson (2007). The social environment, which includes hierarchical power, affects staff and patients (Andrade et al. 2016; Gesler 2003). For palliative and end-of-life patients and families, ritualistic activities such as sharing meals and socialization are essential for meaning and security within the acute hospital setting (Gesler 2003). Yet little is known about how these 4 environments (built, natural, social, and symbolic) affect patients and families when bad news is delivered.

Further research needs to be explored on whether feeling uncomfortable within one's surroundings impacts the ability to absorb important information. Therefore, the study aimed to explore how patients and their families are affected by language and the 4 environments (built, natural, social, and symbolic) when receiving bad news, examined through the Therapeutic Landscapes framework. Research into patient and family member experiences provides evidence to benchmark and plan palliative care service provision (Australian Institute of Health and Welfare [AIHW] 2022).

Methods

Design

While a qualitative exploratory design was used for this study, many techniques described by case study theorists were followed, as the study is part of a more extensive case study examining the phenomenon within Victoria, Australia. The exploratory approach aimed to explore and understand the participants' lived experiences when they received bad news. The Therapeutic Landscapes theoretical framework provided insights to examine social relationships within the hospital's microenvironments closely. Table 1 shows the 4 environments related to the hospital environment within the Therapeutic Landscapes framework.

Population

Adult patients diagnosed with a life-limiting illness who had a diagnostic/prognostic conversation and a hospital admission between 2019 and 2022 were invited to participate in an online semi-structured interview. If an adult family member was present during a diagnostic/prognostic conversation, they were also invited to participate. Participants' diagnoses fell into 2 broad categories: (a) terminal diseases, such as metastatic cancer, that would result in death despite treatment and (b) chronic illnesses, such as heart failure, that could be terminal but could be managed long term. The population studied included patients and their families residing in regional Victoria, Australia, and having treatment in both regional and tertiary care centers in metropolitan Melbourne.

Table 1. Four environments within the hospital

Environments	Components
Built	Ward/room: ambiance, aesthetics, room layouts, amenities, equipment
Natural	Window views, natural light, garden access
Social	Culture, quality of patient care, dominance, power, communication
Symbolic	Public symbols, rituals, meanings, perceptions

Ethical considerations

Wording such as "serious chronic illness" was used on recruitment documentation instead of "life-threatening, palliative, or end-of-life" to reduce unnecessary distress (Virdun et al. 2019). The name and contact number of a support person nominated by the participant were added to the consent form so the researcher could contact them if the participant became distressed during the interview. Federation University Australia granted ethical approval (Number A21-159) on 28 October 2021.

Data collection

Participants were recruited through 5 advertisement posts to the first author's social media community pages across regional Victoria. Thirty interested participants responded and had the project explained to them by the research team. Four did not progress, and 4 were outside the inclusion criteria and were excluded. After screening, 19 were sent a Plain Language Information Statement and Consent Form. Three did not attend the scheduled interview, and 2 interviews were later excluded from the final data set as they did not live in the region. After the first author (E.M.M.) conducted each interview, they wrote their reflections and early meanings-based themes, making them confident that enough rich data had been gathered to answer the research question, and interviewing ceased. Data were collected by applying a semi-structured interview technique using prepared interview questions (Table 2), audio-recorded, and typed verbatim by the first author (E.M.M.).

Data analysis

The de-identified data were coded and analyzed into patterns of meaning (Stake 1995) using reflexive thematic analysis (Braun and Clarke 2006, 2019). This creative and subjective process used the "researcher as an instrument" to engage with and reflect upon the data. After each interview, the first author (E.M.M.) wrote a reflection and insights, which helped inform the following interviews, similar to a constant comparative method described by Merriam (1998, 2009). During transcription, the first author (E.M.M.) typed insights in the margin of the transcript, creating meanings-based tentative codes (Merriam 2009), which helped inform a secondary thematic analysis performed by the 3 authors. This process addressed trustworthiness issues as themes were agreed to through discussion and consensus with the research team.

Trustworthiness and reflexivity

The first author (E.M.M.) is a registered nurse undertaking her doctorate in palliative care and is supported by experienced researchers in critical care and methodology (J.E.P.) and bioscience, health,

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Table 2. Interview questions

1. Please share with me your story about when you (or your family member) was first diagnosed with the health condition
2. Can you tell me about your (family member's) time and experience in the hospital ward?
3. Please describe how Covid-19 impacted your experience while admitted
4. What were your impressions of the ward overall?
5. More specifically, what were your impressions of the:
Built environment (*aesthetics, ambiance, space for family to visit/sleep, and amenities*)
Natural environment (*gardens/window views and access*)
Social environment *(vibe, culture, and social dynamics*)
Symbolic elements (*signs, symbols, and rituals*)
6. What sort of language did the doctor/nurse use?
7. Was the information explained clearly?
8. Do you think WHERE this conversation takes place matters?
9. Please describe what the room looked like where the conversation took place
10. If you were training health professionals on how to conduct family meetings, what would you say?
11. Is there anything you would do differently?
12. Do you think WHO and HOW information about your (family member's) health condition is told to you matters?

Table 3. Participant demographics

No.	Age	Gender	Participant	Malignant diagnosis	Medical diagnosis
1	57	F	Patient	Metastatic breast cancer	
2	30	F	Patient		Metabolic disease
3	72	F	Patient (*dyad*)		AF[a], heart failure
	70	F	Family member (partner)		
4	64	F	Patient	Bowel cancer	Crohn's disease
5	63	F	Patient	Breast cancer	Clotting disorder
6	43	F	Family member (daughter)	Pancreatic cancer	
7	58	F	Family member (wife)	Multiple myeloma	
8	48	F	Family member (wife)		End-stage liver disease
9	34	F	Patient	Cervical cancer	
10	50	F	Patient	Metastatic bowel cancer	
11	68	F	Family member (daughter)		COPD, comorbidities
12	38	F	Patient		Heart failure
13	54	F	Patient	Breast cancer	Multiple comorbidities
14	77	F	Patient	Uterine cancer	

[a] Atrial fibrillation

and methodology (M.S.B.). The first author (E.M.M.) maintained a reflexive journal throughout the entire project and after each interview. In addition, weekly meetings and notes provide an audit trail.

Results

Fourteen individual interviews were conducted with participants between 15 November 2021 and 28 March 2022. Each interview lasted between 45 and 120 minutes and averaged 69 minutes per interview. Patient participants were diagnosed with malignant and nonmalignant conditions by their GPs, specialists, or a physician during hospital admission. Participants were women aged between 30 and 77 years living in regional Victoria; 10 had been inpatients in regional and metropolitan hospitals in the last 24 months, and 5 family member participants had listened to bad news conversations either in person or through telehealth appointments. One interview consisted of a patient and family member dyad. Although both contributed to the interview, their voices could be separated during transcription. Only 3 participants had referrals to a palliative care service, with a further 3 participants researching palliative services themselves. Full details of demographics are given in Table 3. Data analysis resulted in 4 central themes and 2 subthemes that explored the built, natural, social, and symbolic environments of Therapeutic Landscapes that link between the language and environmental elements including “Hearing bad news for the first time,” “Preferences for having hard conversations,” “Creating a sense of safety for ongoing care,” and “The therapeutic nature of the ward.” The latter central theme contained 2 subthemes, “The impact of ambiance and aesthetics” and “The impact of social restrictions.”

Hearing bad news for the first time

Participants were given their initial bad news in GP practices, specialists' rooms, and within the hospital. Those with an established therapeutic relationship with their GP preferred to be told by them, whereas some participants reported that it did not matter where they were told or by whom. Still, it was how they were told that left a lasting impression:

> “I don't think it matters where it takes place, to be honest. You don't want everyone else to hear it, you want to be in a private situation, but I don't think it matters because bad news is bad news wherever you get it. So, it's more about the way it's delivered” (Patient 12, 38 y, medical).

Yet some of the participants receiving a cancer diagnosis within an oncological environment were affected by both the delivery and the environment where the bad news was delivered:

> “I think if you go to see a specialist consultant, you should go to an office, or you don't go into where they're treating the people who've got the same thing as you because it's very confronting, it's overwhelming … because you're in there with people with no hair and it's just very shocking because you're facing your future without warning. You're facing your future before

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> you're told what your future is … and you're mentally fatigued and you're traumatized, and then you've got to try to process the information that the oncologist is giving you. Hypervigilance is the best word to describe what that environment creates" (Family member 6, 43 y, cancer).

The language used by some health professionals also traumatized some participants, with certain words ever-present in their minds. Others struggled to understand the diagnosis's depth due to unfamiliar medical terminology being used without translation. This resulted in internet searching with not always beneficial results.

Not only were patients concerned over the language used during bad news delivery, but the speed and overload of information were also an issue:

> "It was all delivered in a very short time frame in a conversation of less than say, 5 minutes … and he asked me at the end, 'Do I have any questions?' But because I was so shocked about hearing the word cancer, I don't think I could think on the spot and ask anything at that point in time" (Patient 9, 34 y, cancer).

Due to social distancing and lockdowns during the Covid-19 pandemic, some patients were given bad news over the phone or in person alone, yet for many, a support person was essential.

> "No matter how confident or smart or intelligent the patient is, they're just dealing with this overflow of emotion and … their support person, I think [they're] able to take it in a bit better" (Family member 7, 58 y, cancer).

Not only was a support person deemed essential, but participants also suggested a social worker be available for debriefing afterward, especially before a long drive in traffic from the tertiary city hospitals back to regional Victoria:

> "Make sure that we're OK emotionally … that we don't get out the door and … lose our sh*t and drive … home. And for a lot of us in [regional Victoria], that's exactly what happens" (Family member 8, 48 y, medical).

Preferences for having hard conversations

When asked about truth disclosure, participants "preferred to be told the truth … [and] treated like an adult" (Patient 3, 72 y, medical) and for doctors to "be more open and honest with patients about their life expectancy and their diagnosis [to avoid] being given false hopes" (Patient 9, 34 y, cancer). Patients preferred honesty to be tempered with sensitivity and given a warning shot first. They suggested the doctor "needed to build up to break bad news, don't just drop it into the conversation" (Patient 9, 34 y, cancer).

When asked about what could be improved when receiving bad news, Participant 9 suggested "I would be telling that person to be treating patients as though it's their own relatives … you need to take time" (Patient 9, 34 y, cancer) – time to absorb the bad news and then process it; time to ask questions and have them clearly explained, and for the doctor to check that the message was accurately understood. In addition, Family member 8 suggested, "If they're given bad news, they need to triple the length of their appointment time for starters" (Family member 8, 48 y, medical).

Creating a sense of safety for ongoing care

After the initial bad news conversation, all participants were treated in metropolitan hospitals. Due to distance from home and Covid-19 restrictions, family visitation was often problematic, and participants felt anxious about being far from home during an admission. Yet despite the inconvenience of traveling to the city, they preferred the expertise and trust developed with their specialists. Patient 1 felt secure knowing her specialist would support her 24 hours a day, 7 days a week, "[My specialist] is just amazing. I have her mobile number. I can message her at any time of the day or night" (Patient 1, 57 y, cancer). But not all specialists had an amiable bedside manner:

> "[The city oncologist] isn't a people person. Honestly, I came out of there, and I said, 'I'm just another number' … he's not got a good bedside manner … he tells you what he's going to do and says goodbye, basically … But he did his job, he gave me the right treatment for my cancer and all that sort of thing … this is what he does all the time … to me it was new, but to him it's what he does every day" (Patient 13, 54 y, cancer/medical).

Issues arose for many of the participants when they presented to their regional hospitals for treatment or symptom management. On many occasions, participants felt a disconnect between the relationship and care they received from their specialists versus the regional treating teams; "It's like everyone works in silos … essentially nobody takes responsibility. So, everyone's just living till next shift and then they hand it over and then that person lives to the next shift" (Family member 6, 43 y, cancer). Many participants reported not being able to advocate for themselves, with regional teams sometimes not following specialist care plans or medical regimes. This created anxiety and distrust of regional care and resulted in early discharge and calls to their specialists for help; "So, obviously, I went back to my heart specialist. I told her about the situation, and she was really disgusted. So now I have a letter from her that states that if I were to go to [the regional] hospital again, she needs to be contacted immediately" (Patient 12, 38 y, medical). Some participants reported having had prior negative experiences, which developed into a fear of hospitals; "So there was a big fear factor there that these people aren't going to look after me" (Patient 1, 57 y, cancer).

There were many negative comments from participants regarding communication during their or their loved one's regional admission. "All I see them [doctors] is with open folders … writing things down, but they're not actually doing any talking … You're asking them questions, and they would just look at each other, and no one's actually prepared to answer your question" (Patient 5, 63 y, cancer/medical) or "They'll say the generic: 'Do you have any questions?'… You get the feeling that you shouldn't ask any questions. It's like it's a bother" (Patient 10, 50 y, cancer). Two participants were so concerned with their lack of communication and support that they filed formal complaints:

> "I rang every day for 6 days asking for a social worker and I didn't get one … So I just sent off an email [to the hospital] saying, 'Hey, this is what's going on. I'm finding it really challenging. I'm getting no information. I'm needing to pass on very important information to the team, and I can't because no one answers the phone.' [The participant's friend escalated her email to a formal complaint] And all of a sudden, things started to happen. I had the nurse coordinator call me. I had a doctor call me. I had a social worker call me all within 3 hours of a formal complaint being put through" (Family member 8, 48 y, medical).

The therapeutic nature of the ward

The impact of ambiance and aesthetics

Depending on which hospital they attended, participants had mixed responses to room ambiance and aesthetics. A nicely decorated foyer in a city hospital was regarded as tokenistic, while

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the patient's ward remained "an old-fashioned mustard yellow" color (Family member 7, 58 y, cancer). Other participants reported patients' rooms as having "no visual stimuli," "sterile," "bland," "dull," "dreary," "neutral," and "plain and depressing." Participants commented that this affected their emotional experience. Patient 9 (34 y, cancer) suggested that access to a small garden with greenery and tranquil sounds helps during recuperation and that "calming landscapes on the walls and pastel colors is a nice escape." Views of nature through windows were also important "because people need to not feel like they're in a box" (Family member 3, 70 y, medical).

In contrast, 2 participants felt their rooms had cheerful ambiance and aesthetics. "It was very bright and airy. I had a private room. I had a beautiful view. I could see all the lights at night-time" (Patient 10, 50 y, cancer). And another stated [the colors] "were very soft mauves and aqua. … it was relaxing and good, [it had] huge windows, you could see out the windows and it was a pleasant room" (Patient 4, 64 y, cancer/medical).

Regarding the hospital experience, while recuperating after treatment, some were also profoundly affected by the social as well as the physical environment; "But I just know that [the patient] was quite depressed in hospital and a lot of it had to do with his surroundings … [as] the ambiance of the place is not what I call encouraging you to get well" (Family member 7, 58 y, cancer). Put another way,

> "So, if you want to scare someone … you have noises that they don't know, lights and sounds that they're not used to, people coming and going that you don't know or that you don't expect. You give them no routine, you're not told when someone's visiting or not visiting, you sleep deprive them. That's a hospital" (Family member 6, 43 y, cancer).

The impact of social restrictions

During Covid-19 outbreaks, lockdowns across regional and metropolitan Victoria prevented patients from having visitors and socializing with other patients. In addition, nurses were reported as too busy to stop in their room for a chat, and Patient 9 said: "I think I saw the kitchen lady more than anyone, so it was quite lonely" (Patient 9, 34 y, cancer). Forced isolation also caused anxiety and distress:

> "I'd never been away from my daughter before then … and not be able to talk to her … She thought I was dead. She thought I wasn't coming home … I sat on the window ledge, and I cried, and I cried, and I thought, 'If I can just jump there' … I actually contemplated if I could get out that window … That's how bad and how depressing it was not being able to have anyone come and see you" (Patient 13, 54 y, cancer/medical).

As another lockdown period was lifted, Family member 8 reported, "That just knowing that someone was going to come in that he [the patient] was going to see somebody and spend time with somebody – like a switch had been flicked, that he was back in the world of the living, [thinking] 'I'm not just being left in here to die in the dark'" (Family member 8, 48 y, medical).

Discussion

This qualitative study adds depth of understanding about providing a calm and emotionally safe environment where bad news is delivered. In addition, patients feel more supported within a therapeutic relationship, which may enable better absorption of information and reduce unnecessary distress during an emotionally vulnerable event.

Research into the effects of hospitals' physical and social environments on well-being by Andrade et al. (2016) found that although patients' perceptions of their care (i.e., the social environment) were influenced by their first impressions and expectations of the physical environment, the social environment had a more substantial influence. While many participants described their wards' ambiance and aesthetics during admission in either positive or negative ways, the most significant impact on their experience lay within the social and symbolic environments. Within the Therapeutic Landscapes theoretical framework, patients' and family members' perceptions of a therapeutic environment are subjective (Gillespie 2002), and perceptions of their illness and identity as well as their locale within their illness trajectory (Charmaz 1983; Millar et al. 2005) influence their coping mechanisms (Ashley et al. 2015).

The consequence of receiving bad news, which can be a mentally fatiguing and traumatizing event, may result in being on guard, watchful, or easily startled and is one of the indicators of post-traumatic stress syndrome (Nipp et al. 2018). According to Stuart-Smith (2020), when in this high state of stress, memory fails, and new learning cannot be achieved. This may partly explain a patient's inability to absorb the information relating to a bad news diagnosis. Therefore, the patient needs a quiet, calm, and emotionally safe environment before any therapeutic work can begin (Figg et al. 2010; Miller et al. 2022a).

Creating an emotionally safe environment included how bad news was delivered and by whom. The therapeutic relationship between patient and specialist enables tailored bad news delivery, respect, open communication, and trust, which becomes even more important to patients when their future is hard to visualize (Miller et al. 2022a). In contrast, 6 patient participants felt dismissed and not listened to as the expert on their own body and disease experience as they transitioned between their metropolitan specialists and regional hospitals due to poor communication and limited system integration. This caused distress and anxiety as they were not active participants in their health-care decisions, contrary to the remit of person-centered care (Langberg et al. 2019).

As participants reported struggling to absorb bad news and feeling overwhelmed, conversations need to be recurring and incremental aimed at the participant's health literacy level (Miller et al. 2022a). Providing an emotionally safe environment during the delivery of bad news (depending on personal preferences) includes having a support person present to reassure, encourage, listen, and digest the bad news alongside them (Hart et al. 2020; Keeley 2016). Despite palliative care best practice (Australian Commission on Safety and Quality in Health Care [ACSQHC] 2015), social restrictions to prevent the spread of the Covid-19 virus forced many of the participants to be and receive bad news alone, in line with other recent findings (Bloomer and Walshe 2021; Kirby et al. 2021; Pauli et al. 2022).

As 13 of the 14 participants in this study were not classified as being in a terminal phase during the Covid-19 lockdowns, hospital visitor restrictions resulted in patients and family members reporting feelings of depression, helplessness, and isolation when unable to be together during an admission, with similar findings noted elsewhere (Bloomer and Walshe 2021; Pauli et al. 2022). Socialization and routine sharing of meals were blocked, creating a nontherapeutic social environment as only those actively dying could have visitation rights (Department of Health 2022). During a hospital admission, family members could not act as advocates or safeguards against patient deterioration. In addition, family members failed to receive timely updates compounding their distress

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and feelings of helplessness, also noted by Bloomer and Walshe (2021) and Siddiqi (2020). It is argued that the Covid-19 social restrictions have created an environment that is not only non-therapeutic for palliative patients in acute hospitals but potentially psychologically damaging (Kirby et al. 2021; Sudai 2021; Usher et al. 2020).

Strengths and limitations

The study was designed, approved, and conducted during the Covid-19 pandemic, limiting recruitment methods to social media advertisements and data collection via telephone or online interviews. These factors, including pandemic fatigue, may have reduced the study's visibility, interview preference, and uptake. Two men were scheduled to interview but withdrew, creating a female-only sample from one sizable regional area. Therefore, these results may not be representative of other populations or regional zones in Victoria and, therefore, not generalizable. The interviewer is a registered nurse (while not practicing clinically) who has prior training in pastoral counseling and was able to quickly develop a rapport with the participants, resulting in rich data being collected.

Conclusion

To improve the absorption of diagnostic/prognostic information and remove unnecessary distress during bad news delivery, it is essential to consider the impact that the built, natural, social, and symbolic environments have on patients and family members and create a quiet, calm, and emotionally safe environment maintained within a supportive therapeutic relationship. This research will add to the body of knowledge to inform future practice and policy to improve the experience of patients and family members.

Author contributions. The first author (E.M.M.) contributed substantially to the project's conception and design, recruitment, data collection, and analysis and wrote the manuscript. This work forms part of their doctorate. The second (J.E.P.) and third authors (M.S.B.) assisted with the conception and design, data analysis, and edits of the manuscript and supervised throughout the project. All authors have read and agreed to the final manuscript.

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