

# ‘It all depends!’ – Preferences for place of care and place of death in terminally ill patients and their carers

Katrin Gerber<sup>1</sup>, BARBARA HAYES<sup>2</sup>, and CHRISTINA BRYANT<sup>2</sup>

<sup>1</sup>University of Melbourne

<sup>2</sup>Affiliation not available

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## Abstract

**Background:** It is often suggested that terminally ill patients favour end-of-life care at home. Yet, it is unclear how these preferences are formed, if the process is similar for patients and carers, and if there are discrepancies between preferences for place of care and place of death. Understanding these nuances is essential to support people in their decision-making and ultimately provide better care at the end of life.

**Aim:** To gain an in-depth understanding of how terminally ill patients and their family caregivers make decisions about preferred place of care and place of death.

**Design:** Semi-structured interviews with patients and carers, which were analysed thematically using qualitative description.

**Setting/ participants:** A total of 17 participants (eight patients and nine carers) recruited from an acute palliative care hospital ward, a sub-acute hospice unit, and a palliative

homecare organisation in Melbourne, Australia.

**Results:** The process of forming preferences for place of care and place of death was shaped by uncertainty relating to the illness, the carer and the services. Participants dealt with this uncertainty on a level of thoughts, emotions, and actions. At the end of this process, participants expressed their choices as conditional, personal, relational, contextual and flexible preferences.

**Conclusions:** End-of-life decision-making rarely ends with a clear and stable choice. Understanding the reasons for the malleability of preferences and the process of how they are

formed has implications for both clinicians and researchers.

*Original Article*

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in terminally ill patients and their carers**

**Authors:**

Katrin Gerber<sup>1</sup>, Barbara Hayes<sup>2, 3</sup>, Christina Bryant<sup>1</sup>

<sup>1</sup> School of Psychological Sciences, University of Melbourne, Victoria, Australia

<sup>2</sup> Advance Care Planning Program, Northern Health, Bundoora, Victoria, Australia

<sup>3</sup> Palliative & Supportive Care, Royal Melbourne Hospital, Melbourne, Victoria, Australia

**Corresponding author:**

Katrin Gerber c/o A/Prof Christina Bryant, Redmond Barry Building, School of Psychological Sciences, University of Melbourne, Parkville VIC 3010, Australia, E-mail:

kgerber.research@gmail.com

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**Keywords**

Palliative care, decision making, terminal care, qualitative research, patient preference, caregivers

**What is already known about the topic**

- Home is often advocated as the most preferred place of care and a marker of a ‘good death’.
- It has been suggested that preferences for place of care and place of death are not the same and often change over time.
- Palliative care literature is outcome-focussed, which means that many studies examine preferences without addressing how these are formed.

**What this paper adds**

- Decision-making does not always end with a clear and stable choice because the answer to the question ‘Where would you like to be cared for and die?’ was most often: ‘It depends.’
- Patients and carers had to find the balance between not knowing enough and knowing too much, and to do this, they used cognitive, emotional and behavioural strategies.
- Forming preferences was a conditional, personal, relational, contextual and flexible process.

**Implications for practice, theory or policy**

- As preferences are built on uncertainty, clinicians and researchers need to understand the underlying reasons that inform patients’ and carers’ wishes, and seek to anticipate, accept, and accommodate the malleability of preferences at the end-of-life.

## Introduction

As healthcare systems are confronted with increasing numbers of ageing and terminally ill patients, the question of where people want to be cared for has received considerable attention. Studies suggest that the answer is most often: 'Home'.<sup>1,2</sup> Being at home, surrounded by family and friends, can offer psychological comfort for patients by providing a familiar environment that they have some control over.<sup>3</sup> Consequently, dying at home is now often regarded as a marker of a 'good death' and a success indicator of the healthcare system. This, however, is a development that some researchers and clinicians are cautious about because dying at home is not always as ideal as it sounds.<sup>4-6</sup> Based on interviews with 276 bereaved carers, Parkes<sup>7</sup> found that symptom management and exhausted families were common problems of end-of-life care at home. They concluded that 'home can be the best place or the worst place to die' (p. 26).

Care of the dying has become a complex medical science and hence, professional support is often needed. While many people want to receive end-of-life care at home, they do not necessarily want to die there. Agar et al.<sup>8</sup> found low congruence between preferences for place of care and place of death in a longitudinal study of 71 Australian palliative care patients and carers. They were critical that in clinical practice and research these two concepts were not clearly separated, and even used interchangeably. Thomas, Morris and Clark<sup>9</sup> added that in interviews with 59 patients and carers, many expressed no preference for place of death, had not yet decided or favoured more than one place. This caused the authors to be 'wary of the apparently resolute character of preference as reported in more quantitative research literature' (p.2442). End-of-life preferences are often examined as if they are the end result of decision-making, yet there is evidence that choices are not stable and change over time.<sup>8, 10, 11</sup> The aim of this qualitative study was therefore to gain an in-depth understanding of *how* terminally ill patients and their family caregivers form preferences for place of care and place of death.

## Methods

### *Sampling and Eligibility*

Purposive sampling was used to recruit adult patients diagnosed with a life-limiting illness deemed unresponsive to curative treatment, and a prognosis of less than 12 months as assessed by the treating team. Participants had to be aware of the diagnosis and the terminal nature of their illness. They needed sufficient English skills to give informed consent and be interviewed in English. They had to be physically well enough to participate and have no significant cognitive impairment. Finally, patients needed to have a primary informal caregiver, who was also invited to take part.

### *Interview guide*

Face-to-face interviews followed a semi-structured guide (see Figure 1), which was developed through literature review and discussions within the research team and refined during the study.

*Figure 1.* Interview guide.

#### First Preference:

- Where would you like (the patient) to be cared for?
- What does this place mean to you?
- What do you need in order to achieve this preference?
- What do you think might prevent this preference?

#### Second Preference:

- If [the first preference] was not possible what would be the next best option?
- What does this place mean to you?

#### Last Preference:

- What would be your least preferred place of care?
- What does this place mean to you?

<p>What would have to happen for you to be okay with being in [least preferred place]?</p> <p>Other Options:</p> <p>Would somebody else's home be an option?</p> <p>What do you know about palliative care?</p> <p>Have you heard of hospice care?</p> <p>Importance:</p> <p>How important is this decision for you?</p> <p>Place of care vs. Place of death:</p> <p>Do you think where you want to be cared for and where you want to die are two different questions? Or is it the same?</p> <p>Can you explain why you think that?</p> <p>Discussion:</p> <p>Have you discussed your preferences with your carer/ the patient?</p>
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### ***Settings and procedure***

Participants were recruited from three settings in Melbourne, Australia: an acute, palliative care hospital ward; a sub-acute hospice unit; and a palliative homecare organisation. Ethics approval was obtained from the Human Research Committees of Melbourne Health (Project: 2013.260, Date: 28.01.14) and Northern Health (Project: P02/14, Date: 14.05.14). Data was collected between February and December 2014. At the two in-patient settings, the treating team identified potential participants, who were then approached in person by the researcher (K.G.). In the community setting, patients received a postal letter inviting them to contact the researcher directly.

Overall, 41 potential participants were identified. Of those, 24 were not interested in the study, did not want to discuss end-of-life topics or were too busy. The remaining 17 provided written consent. Interviews were conducted by the primary investigator (K.G.), who was not involved in patients' care. Interviews were audio-recorded, varying from 15-86 minutes ( $M = 51$  minutes). Participants were interviewed during a single session in a place of their choice.

Twelve interviews were conducted in participants' homes, one in the patient's workplace, and four in private rooms in the participating wards. Five patient-caregiver dyads chose to be interviewed together, while the remaining three patients and four carers preferred one-to-one interviews.

### ***Data analysis***

Audio-recordings were transcribed verbatim and coded with NVivo software. Qualitative description was used for analysis<sup>12</sup>, involving: open coding (breaking raw data into initial codes); axial coding (merging codes with similar information and establishing relationships between themes); and selective coding (organising codes into overarching themes)<sup>13, 14</sup>. The appropriateness of the themes was checked through continuous iterations and reapplied to earlier transcripts. This process was repeated until no new themes were found.

### **Results**

In total, 17 participants were interviewed (eight patients; nine carers). As summarised in Table 1, patients were on average 75 years old, the majority were male and had malignancies. Carers were around 69 years of age and most often the patient's spouse. By the beginning of data analysis, all patients who had participated, or whose carer had taken part in the interviews, had died.



Table 1

*Personal, inter-personal and illness-related background of the interviewed participants*

	Patients <i>n</i> = 8	Caregivers <i>n</i> = 9
Average age in years ( <i>SD</i> ),	74.63 (9.54),	69.00 (11.20)
Range	64-87 years	54-84 years
Percentage of females (number)	37.50% (3)	44.44% (4)
The patient/carer is your...		
Current or former partner/ spouse	87.50% (7)	77.78% (7)
Parent		22.22% (2)
Child	12.50% (1)	
Percentage of patients or carers referring to a patient with a malignant diagnosis (number)	75.00% (6)	66.67% (6)

Four overarching themes were identified related to how preferences were formed: (1) Uncertainty; (2) Cognitive responses; (3) Emotional responses; (4) Behavioural responses.

### ***Uncertainty***

Uncertainty was broadly expressed as a state of not knowing what to expect from an unpredictable future, as this carer described:

I think she (the patient) would rather be with me at home. I think that. You can ask her that. I'm not sure. But at this point, it depends on how she dies. And I can't get anything out of the doctors, could be a slow decline, or it might be bang... You're always working with that sort of dimension called hope or lack of hope. Of course you are.... Prognoses aren't certain. Cause it's not like they say: 'OK, here is a chart and here is this point, this is when they're dead'. Cause it's not what happens. (Carer 7, male, non-home)

Uncertainty was the most dominant theme in the interviews and three types were discussed:

- Illness-related uncertainty: Being unsure how the illness would progress, what symptoms/ care needs the patient will develop, how much time they had left and how they would die.
- Carer-related uncertainty: Being unsure how the carer would cope, emotionally and physically.
- Service-related uncertainty: Being unsure what support services would be available and how to access them.

Different settings were associated with different uncertainties. Home was the most preferred place of care, which was initially seen as the safest option because it was familiar. Here, participants described feeling comfortable, free, independent, in control and at peace. However, at home, illness- and carer-related uncertainty was high. Patients were unsure if homecare would over-burden their family, which strongly influenced their preferences:

If I felt I was being a burden, then I'm very willing to forego my desire to be at home, to go where I'm not a burden. (Patient 6, male, home)

Carers were similarly unsure about how they would cope with caregiving demands. This depended on: availability of support; the patient's medical/ personal needs; conflicting carer responsibilities like work; and the carer's own physical/ mental health. To manage these uncertainties and provide good care at home, caregivers described needing help through family members, friends, and medical staff. But many had only a vague understanding of what palliative homecare is and how to access it, which added to service-related uncertainty. For instance, one dyad reported hearing 'fairly good reports' about 'this palliative care business' although being unsure what this actually meant, associating it with a special hospital care for imminently dying patients.

Despite high uncertainty at home, carers described being very committed. They wanted to honour the patient's wishes, but were unsure what was manageable:

I'd like him (the patient) to come home. But I want him to go home when he is ready. 'Cause if he were to come home and then after two, three days he gets sick again, it's a bit too much for him to come and go. So we have to ask the doctor what they think - if he is good enough to come home. (Carer 9, female, non-home)

As with this example, preferences were rarely absolute and often expressed as conditional tendencies to favour one place over another. Carers were unsure if they could fulfil their patients' care needs as they approached death, and thought a more professional setting might be required. There was a threshold at which the demands of homecare exceeded the carer's abilities to cope and providing best care meant relocating to an institution. Under those circumstances, home was no longer the safest option and overruling or re-evaluating the patient's wishes was considered necessary - in the interests of both:

I have talked to [patient] and I don't think I would be able to cope with looking after him here, at the very end. You know, because I don't want those memories of how sick he was at the end each time I come in through the door... You don't want to keep a memory of seeing your loved one just laying in that room, in that bed. Because that would stay with me forever. (Carer 1, female, home)

Similarly, many patients preferred not to die at home, to avoid long-term harm to their family:

I don't want to die at home here, because if I do it'll haunt [carer]. He doesn't think it but I know from my own self that it'll haunt him knowing that he's seen me die at home. I think it's better if I'm dying in the hospital. That would relate better to him, you know. That's what we've decided. (Patient 3, female, home)

When homecare was not possible anymore, participants considered hospitals or hospices, which provided instant access to medical help and equipment. This reduced illness- and carer-related uncertainty. Yet, here care was provided by strangers in unfamiliar settings with unfamiliar routines, which was a trade-off that needed to be considered. In institutions, service-related uncertainty concerned the communication, structure and hierarchy of the setting.

Participants also discussed not knowing how long they could, or had to stay, and if they could return home:

I don't know who runs things here. I don't know if there's one top person... It's probably the doctors that ultimately say 'yay' or 'nay' here. But I'm not sure of that. And I'm not sure that they're always in agreement, you see... There's a bit of uncertainty there... Because when you come into a place like this there is no one who says: 'This is the structure.' You just come in, and pick up what's happening. No one ever says: 'This is how it works.' (Carer 7, male, non-home)

While most participants accepted hospital or hospice care as sometimes necessary, nursing homes were considered extremely unsafe. They were described as 'understaffed', 'underbudgeted' - 'a money-making venture' where 'it's not about the care of the patients'. This increased illness-related uncertainty:

My attitude is that they [nursing homes] are waiting rooms. You go there to wait to die. Sometimes it takes a long time. Sometimes it doesn't. But essentially it's where you deposit people that you don't want to care for at home or you can't care for at home. (Patient 7, male, home)

Participants felt strongly about avoiding nursing homes at all cost. They were said to offer no stimulation, no dignity and people were believed to die there more quickly. Residents were described as 'abandoned', 'left alone', 'drugged up', and even 'locked up'.

As decisions were made in extremely unpredictable circumstances, participants discussed a strong need to seek certainty and thereby achieve a sense of safety. However, as illustrated in Figure 2, there was a tipping point at which too much certainty was perceived as confronting and sometimes even avoided. Individuals differed in how well they could tolerate uncertainty and which strategies they used to feel safer. To find a balance between not knowing enough and knowing too much, participants responded on a level of thoughts, emotions and actions.

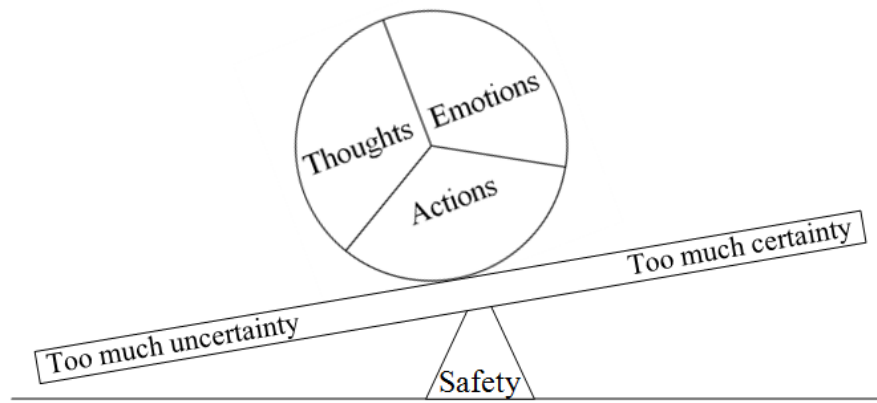


Figure 2. Balancing (un-)certainty through emotions, thoughts and actions.

### ***Cognitive Responses***

Uncertainty triggered cognitive responses relating to three sub-themes:

*Memories and past experiences:* Experiences with care settings strongly influenced participants' attitudes towards these places of care. Positive encounters with institutional settings helped reduce uncertainty about what to expect and increased the sense of safety with going there. In contrast, unfamiliar wards were considered more frightening. When participants had insufficient first- or second-hand experiences to draw from, they referred to reports heard from others or the media:

Patient: [Nursing homes are] a money-making venture and it's not about the care of the patients. And you hear that a lot with what's reported in the media. So that influences the way I think about it.

Carer: From a personal point of view, I haven't had a lot to do with nursing homes, so it's not from a personal experience.

Patient: Yeah, it's only hear-say. (*Patient 6, male and Carer 6, male, home*)

*Hypothetical scenarios:* Participants weighed their options using self-constructed, hypothetical scenarios – both good and bad. They considered under which circumstances homecare was manageable and when institutional care became necessary. 'If... then...' scenarios were a form of mental preparation for the future used to reduce uncertainty:

If I have a problem and she seems to be in pain, I ring the nursing service, they talk me through it. Tell me what to give her ... And I might say: "I'll try that." If that doesn't work, they will come. And if they decide, they can't do anything about it, it's triple O again and off to [hospital]. So the fail-safe's there. (*Carer 7, male, non-home*)

***Worries about the future:*** While considering different scenarios was sometimes described as helpful, there was a tipping point at which too much thinking ahead caused more uncertainty instead of less and people started to worry. At home, this concerned patients' pain/symptom management, personal care and carers' ability to cope. Worries in institutional settings included matters of privacy, setting cleanliness, personal hygiene, dignity and independence. Structural aspects like proximity to family, availability of services and financial concerns were also discussed:

That sort of worries me a little bit. Because I don't wanna be just left, on my own, for hours on end and not being able to do the things... But it's all the unpleasant things like the hygiene and things like that that concerns me now. (*Patient 1, male, home*)

### ***Emotional Responses***

Preference forming was not purely cognitive but also an emotional process. Feelings discussed in response to uncertainty related to two sub-themes:

***Challenging emotions:*** e.g. fear, shock, sadness, disappointment and regret. Patients often reported being upset, emotionally stressed and helpless:

I can feel now, I could get emotional if I wanted to. ... I was very fearful. Terrified! I felt terrified of death and dying and the unknown. I was always a person, I had my life in check and knew where I was going... When this happens to you, everything stops. It's like someone sliced your life down the middle and you're not going to do any of the things you thought you're going to do. And so with that comes fear of the life ending and wanting that life. (*Patient 5, female, home*)

In contrast, carers talked about being exhausted, unprepared and overwhelmed. There was a sense of responsibility in a burdened way. Yet, while making end-of-life decisions in an unpredictable context was described as challenging and upsetting, emotions were also a source of great strength.

*Strengthening emotions:* e.g. hope, courage, trust, happiness and contentment. Many used humour as a coping mechanism and expressed gratitude, reciprocity and commitment:

Patient: I'd stay at home, battle it out at home.

Carer: Always the two of us...

Patient: As long as the two of us got our marbles together, we'll battle through.  
(Patient 4, male and Carer 4, female, home)

### ***Behavioural Responses***

In the interviews, two main behavioural strategies were discussed to deal with uncertainty:

*Active preparation:* For carers, this mainly meant learning. They gathered information about the illness, alternative treatments and care settings. They learnt medical jargon, sought support and set up their home for care. For patients, preparation meant talking about their wishes and negotiating preferences with respect to their family's needs. Many had made specific end-of-life arrangements by giving belongings away, completing a living will or even funeral planning:

A Mass, nice and quiet... I'd be happy with that... It's nice to know in a way, you know, when you're going to die... I think it is, because you can make some of your own arrangements. Like I had a ring that [carer] bought me for our 25th wedding anniversary. And at the back of my mind I always thought that my daughter-in-law will have that... And I gave it to her yesterday. Why wait till after I die? (Patient 2, female, non-home)

For some, active preparation reduced uncertainty as it provided a sense of control and lessened the burden on the family. Yet, the unpredictability of the context also demanded some flexibility and planning far into the future was described as not possible.

*Active Avoidance:* While planning ahead offered some sense of safety, too much certainty was sometimes perceived as confronting and anxiety provoking. In these cases, considering end-of-life decisions made participants feel unsafe. They hoped for more life with further treatment or even ‘miracle cures’. They were unwilling or unable to contemplate dying yet. Instead, active avoidance was chosen as a strategy to cope with the unpredictable circumstances. Some preferred not to receive too much information about the illness and focused on hopeful reports. Discussing and planning for death, even when prompted by doctors, was seen as giving up. Instead, these conversations and decisions were postponed to some future time when death was closer - ‘down the track’, ‘not yet’, ‘we cross that bridge when we come to it’. For instance, when asked if he had discussed his end-of-life wishes with his carer, this patient said:

No, no, no. Not yet. Because we’re still in the positive mode... It's a conversation that will take place, you know, but at the moment, it's a long way away. And I'm happy for it to stay there, for the minute. Because the more I think about that, it means the time focus is narrowing. (Patient 7, male, non-home)

Hence, not dealing with it (yet) was their way of dealing with it. Avoidance was also chosen to protect others. Some participants did not discuss certain issues or actively concealed information that would lead to conflict or upset their family:

That's not something we've actually talked about with her (the patient) because I think that would throw her into tumult, and we thought: Oh, let's wait until that needs to be dealt with... It would just upset her. (Carer 8, female, home)

In summary, both avoidance and planning ahead were strategies used in highly unpredictable circumstances. They were strongly interconnected with the emotional and



cognitive responses outlined. Behavioural strategies changed frequently depending on the situational demands. For example, after making challenging end-of-life choices, patients and carers returned to day-to-day activities, which provided a sense of normality. Similarly, those who preferred not to deal with end-of-life issues were sometimes forced to make decisions and 'pause' their avoidance. While some favoured one approach over another, many appeared to change from avoidance to planning and vice versa.

## **Discussion**

### ***Main findings***

This study aimed to gain an in-depth understanding of how terminally ill patients and family caregivers make decisions regarding place of care and place of death. Consistent with previous research, many participants expressed a preference for home.<sup>1, 2</sup> But decision-making did not end there. Patients were concerned about what homecare meant for their family's wellbeing, and carers worried how to manage their patient's needs. This supports Thomas, Morris and Clark<sup>9</sup> who found that location preferences were not always clearly defined, advising caution regarding the resolute character of preferences reported in quantitative literature. In the current study, institutional settings were also considered, especially as place of death. While patients favoured care at home, many did not want to die there to avoid long-term harm to their family. This provides evidence for the argument of Agar et al.<sup>8</sup> that preferences for place of care and place of death need to be assessed separately. The current study adds further insights into the process of forming location preferences, which can be summarised as contextual, personal, relational, conditional, and flexible:

**Contextual decision-making.** Preferences were formed in a context characterised by uncertainty regarding the illness, the carer and the services. Many participants tried to achieve a sense of certainty through information seeking, discussions and planning. Yet, too much certainty was perceived as confronting and hence, sometimes avoided.

**Personal decision-making.** Preferences were based on participants' personal history. Past experiences shaped their attitudes towards care settings and hence decision-making. Individuals differed in how well they could tolerate uncertainty and which strategies they used to manage it. Some felt safer by not knowing what was to come, while others actively planned for the future.

**Relational decision-making.** Preferences were negotiated between patients and carers. The views of medical staff and other family members were also considered. While the focus was on the patient's wishes, decision-making was shared. Preferences were based on concerns for each other, relationship aspects, and a sense of responsibility and reciprocity.

**Conditional decision-making.** Preferences were rarely absolute, but instead expressed as conditional tendencies to favour one place over another. If the first preference was not feasible, other settings were considered. Hypothetical 'if... then...' scenarios allowed participants to make plans despite this uncertainty.

**Flexible decision-making.** Even when preferences had been established, there was an acceptance that they might not be achievable. This flexibility allowed participants to change their mind if they wanted or had to. It also created a 'taking it day by day' mentality because planning far ahead was regarded as not possible due to the unpredictability of the circumstances.

### ***Strengths and limitations***

By recruiting patients within their last year of life, this study is one of the few that captured true end-of-life perspectives rather than relying on long-range predictions of non-terminal samples or retrospective reports. It further added the views of family carers instead of assuming that their wishes align with the patients'. Participants were recruited from three different settings, providing diverse experiences. However, responses may have been biased by social desirability, especially when dyads were interviewed together. Also an underrepresentation of participants

using active avoidance as a strategy is probable as avoidant individuals are unlikely to volunteer for end-of-life research.

### ***Implications***

This study highlights that end-of-life decision-making rarely concludes with a clear and stable choice. Instead, clinicians and researchers need to anticipate, accept, and accommodate the malleability of preferences. Just as we ask patients about their current level of pain and know this might change over time, we need to approach preferences with the understanding that they too can change. Healthcare systems have to cater to this instability of choices and respond to patients' needs at short notice. Furthermore, instead of asking only: 'Where do you want to be cared for and die?', we also need to ask: 'Why?'. To identify under what circumstances preferences exist, persist and change, we need a continuous dialogue between healthcare professionals, patients and families about their wishes and the reasons behind them. Since the instability of location preferences reflects the instability of circumstances at the end-of-life, communication is of the utmost importance. This means that clear language must be used that does not confuse place of care with place of death, and clinical staff need to be equipped with the necessary skills, time, and resources to engage in meaningful discussions rather than making preference assessments a tick-box exercise.

### **Conclusions**

When asked about their preferred place of care and place of death, the answer of most patients and carers was: 'It depends.' Preferences changed with the demands of the situation and the uncertainty that came with it. Views were negotiated while considering patients' needs, carers' abilities to cope, and the availability of support. This malleability of preferences requires care systems that are accessible, receptive and flexible enough to respond to the ever-changing needs of those facing the end-of-life.

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**Availability of data and materials**

The audio-recorded interviews and transcripts are not available to protect participants' privacy. However, additional information regarding the themes presented can be requested from the corresponding author.

**Declaration of conflicting interests**

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**ORCID ID**

Katrin Gerber <https://orcid.org/0000-0002-5015-6420>

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