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## Placing death and dying: Making place at the end of life

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## ABSTRACT

Over the last decade, policies in both the UK and many other countries have promoted the opportunity for patients at the end of life to be able to choose where to die. Central to this is the expectation that in most instances people would prefer to die at home, where they are more likely to feel most comfortable and less medicalised. In so doing, recording the preferred place of death and reducing the number of hospital deaths have become common measures of the overall quality of end of life care. We argue that as a consequence, what constitutes a desired or appropriate place is routinely defined in a very simple and static 'geographical' way, that is linked to conceptualising death as an unambiguous and discrete event that happens at a precise moment in time in a specific location.

In contrast, we draw on 18 months of ethnographic fieldwork with two inner-London palliative care teams to describe the continual work staff do to make places suitable and appropriate for the processes of dying, rather than for a singular event. In this way, instead of 'place of death' merely defined in geographic terms, the palliative care staff attend to the much more dynamic relation between a patient and their location as they approach the end of their life. Central to this is an emphasis on dying as an open-ended process, and correspondingly place as a social space that reflects, and interacts with, living persons. We propose the term 'placing work' to capture these ongoing efforts as a patient's surroundings are continually altered and adjusted over time, and as a way to acknowledge this as a significant feature of the care given.

## 1. Introduction

Palliative care refers to symptom management and pain relief for conditions that cannot be cured; it therefore can be provided to anyone with an incurable condition, not only those who are at the end of life. Conversely, while contemporary end of life care can include palliative treatment, is also includes social, emotional and often religious support to encompass what is termed a holistic approach to patient care. In this paper, we explore a dominant feature of end of life care as provided by specialist palliative care teams – that concerning place of death. Over recent years there has been an increasing focus on the importance of place of death both in the UK and internationally (Cohen and Gott, 2015, p. 107; Collier and Broom, 2020). In the UK, this has been enshrined not only in formal policies that promote attending to the place of death (e.g. Department of Health and Social Care, 2008) but also a national focus within health service delivery to document where people die (e.g. Public Health England, n.d.).

As part of this, dying at home is often singled out as the most

appropriate and desired place for many people, with dying in hospital considered the least suitable (Teggi, 2020; UK National Palliative and End of Life Care Partnership, 2015, p. 27stein). This trend to foster greater numbers to die at home has been the result of a convergence of different perspectives, most notably; mounting criticism that end of life has become overly medicalised (Worpole, 2020), recognition that patients dying in a hospital creates a huge burden on secondary care resources (Caley and Sidhu, 2011), and increasing awareness that health systems in the future will need to provide end of life care to more people, for more extended periods of time (Gomes and Higginson, 2008). Dying at home is thereby conceived of as a response to the growing imperative to respect patient dignity and autonomy while at the same time addresses the need for healthcare systems to save costs and reduce burden on secondary care provision (Pasveer et al., 2020).

Understood simply as someone's usual place of residence, which can include their long-term care home, home is frequently presented as a place that self-evidently and unproblematically provides comfort and safety, and hence a place where someone can 'die well' (Pollock, 2015;

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Visser, 2019). In the UK, the promotion of home as the most suitable place to die is further embedded in the notion of a patient's 'preferred place of death' (PPD), which has become a key idiom at the heart of current policy (Munday et al., 2007). Initially it was used in guidelines to encourage professionals to have conversations with patients about where they might want to die, in order to plan for how this could be supported (Department of Health, 2009; NHS England, 2014, pp. 18–19). The thinking was that by having such discussions, patients would have the opportunity to reflect on their options and, often, realise that dying at home was best for them. This has generated audit practices that draw on the correspondence between preferred place of death and actual place of death to provide a quality measure of end of life care (Ali et al., 2019). However, doing so also has created the potential of 'double failure' for professionals looking after people at the end of life (Bishop, 2011): not only do they have to deal with the fact that a patient will not recover, but also that, if a patient does not die at home, they have in some way fallen short of their duties (Cherny et al., 2015).

Despite a longstanding history of social science engaging with the notion of 'home', as well as 'private' and 'the domestic' (for a review, see Brickell, 2012), the term in much end of life discourse continues to be used uncritically (Collier and Broom, 2020). The reality is that home is often not so straightforward (López Gómez and Estrada Montalà, Mariona Canal Farré, 2020), and places cannot in themselves be considered inherently 'good' (Gott et al., 2004). For many, home may not carry positive connotations (Rainsford et al., 2018), or it might be experienced as 'risky' (Mallett, 2004; Markkanen et al., 2007), while for others home may not be geographically defined at all (Baldassar et al., 2020). Additionally, by emphasising the desirability of home as a place of death modern biomedical care inevitably extends its medical gaze into more private and domestic spaces (Liaschenko, 1994), while problematising dying in institutional care settings (Collier and Broom, 2020; Robinson et al., 2016). Yet the reality is that for some patients hospitals may well be the most appropriate place to die, providing a sense of safety and structure not only for patients but also their carers (Collier et al., 2015).

We therefore want to complement critical commentaries about the concept of home and the rhetoric of choice in much end of life policy (Borgstrom, 2015) by focusing on the assumption that asking someone where they may wish to die is routinely equated with recording the response as a fixed and stable location. This not only negates the sense of instability which is part of the experience of dying, but ignores many of the complex changes that a person at the end of life, and those around them, have to face (Macartney et al., 2016). In the process of dying, the person, their bodies, and their relationships with others often go through quite significant changes (Lawton, 2000). But so too does the meaning and material reality of a place – whether home or elsewhere (Douglas, 1991; MacArtney et al., 2015; Milligan, 2009; Pasveer et al., 2020). It is therefore the ongoing relationship between a person who is changing, and the environment around them altering, that we wish to explore here.

From 'matter out of place' to 'placing matter and mattering place'.

During our work with two palliative care teams in London, UK, it became increasingly clear that staff are very aware of a range of tensions that arise from a crude conceptualisation of place captured by recording PPD, and the assumption that home is always the best choice for patients in their last days. Whilst they did not reject the overall policy drive to support and encourage dying at home, their everyday contact with patients and appreciation of individual circumstances foregrounded the ways that symbolic and emotional dimensions are an intrinsic aspect of any preference a person might make. In this paper we therefore describe how staff work alongside patients, and often also their relatives, to make places feel secure and familiar – irrespective of where exactly that may

be. In doing so, we argue that a substantial amount of palliative care effort goes in to what we call 'placing work', which constitutes a significant, if invisible, feature of the care they provide.<sup>1</sup>

Within anthropology, the link between the material and the symbolic continues to be exemplified by the work of Mary Douglas. She not only suggests that a society's moral order is transposed on to the material world, but that the material world often, in turn, serves to represent the moral in physical form (Douglas, 1966). Crucially, the focus of this approach is on the mobility of material objects, and the degree to which they are seen to 'fit' into an existing classificatory architecture; things that are deemed to be in the wrong place, or have no place at all, threaten that order. Thus, symbolic meaning is derived from the location of objects within a cosmology, rather than from their specific nature. However, this focus on material things means that they are, by default, intrinsically stable, and that there is always an absolute distinction between symbolic representations and the things themselves.

More recent literature in the social sciences, in contrast, has foregrounded the way in which entities are continually appraised, appreciated and constructed, highlighting how a great deal of work is often required in order for things to appear stable and constant (Laet and Mol, 2000; Law, 2004a). For example, taking his cue from Barad's position that 'The world is an ongoing open process of mattering' (Barad, 2003, p. 817), Law theorises this practice of 'matter-ing' (2004b). This approach shifts the traditional concern with the stable nature of things to one of socio-material processes that serve to fleetingly enact things into being. The move challenges Douglas' approach which, by solely emphasising the significance of an object's location implies its materiality is constant, and instead insists not only that stability is ongoing and fragile, but that place and matter are always relationally entangled.

In this paper we draw on this theoretical approach in the context of end of life care. Taking this matter-ing to be central, we explore how clinical decisions, patient preferences and the places where care is done not only interact, but constantly shift in relation to each other. In contrast with the singular notions of both place and death, as articulated by current policies and the more formal accounts used in current healthcare management, we explore how concerns about place continually emerge from the interactions between staff, patients, and the material environment, and how this 'placing work' reflects the ongoing, and often unpredictable processes of dying. We conclude by discussing the implications attending to this work has, and suggest how this notion may be relevant in other settings.

## 2. Studying the work of placing: Methods

By adopting a theoretical orientation that foregrounds interactions and ongoing processes, we decided to use ethnography because it provides rich qualitative description and emphasises the very situated nature of social life. The data for this article is drawn from eighteen months of fieldwork conducted between May 2018 and December 2019 with two London palliative care teams; one based in the community and the other in a large teaching hospital. As part of a research project funded by the ESRC (ES/P002781/1), each of us came with a depth of previous relevant experience: Annelieke had conducted extensive ethnographic research with older people with dementia; Erica had been a specialist in end of life research for over a decade; and Simon had been involved in a number of hospital ethnography projects, including one on Do Not Resuscitate orders.

Both palliative teams included specialist care nurses, consultants, and administrative staff as well as occupational therapists, and physiotherapists; one team had a part-time psychologist, the other had two

<sup>1</sup> We chose the notion of 'placing work' to differentiate it from 'placing', a term Natassia Brenman coined to highlight how places participate in the enactments of (non-)belonging, and denote the ways in which precarity emerges from socio-material arrangements of UK mental health care (Brenman, 2021).

part-time social workers. Weekly multidisciplinary team meetings (MDTMs) also frequently included staff from other support services, such as psychiatrists, bereavement officers, spiritual carers, and specialised mental health services. Although both teams worked in close contact with hospices, our study did not include the involvement.

The reality of conducting an ethnography means that there can be no clear distinction between theory and data, since the process of data collection is, in an important way, also an act of its construction. Fieldwork consisted of observing over 70 MDTMs, and shadowing staff members, which entailed accompanying individuals on their visits to patients on hospital wards or in the community. After each observation we wrote fieldnotes and reflexive prompts to develop ongoing data collection and analysis. To complement and contextualise the observational data, we also interviewed a range of the professionals and some patients. In total, 21 staff interviews were conducted with 20 staff members, and were transcribed verbatim. These transcripts were shared with interviewees if they requested it. The research team also gathered documents related to the provision of palliative care within London, such as service reports, commissioning guidelines, and media coverage (for more detail on our methodological choices and musings, see [Borgstrom et al., 2020](#)). The palliative care teams were regularly consulted about our preliminary findings via presentations and ‘collaboratories’ (collaborative workshops). These provided an opportunity for feedback and exchange ([Hoppe et al., 2019](#)) in order for us to add to, refine and validate our study findings, as well as provide practical insight and reflection for staff.

Given the multifaceted nature of fieldwork, everyone we directly encountered in the study was given the option to consent to participating in one or more of the different elements of data collection. All names in the text are pseudonyms. Ethical approval for the study was obtained from all relevant parties: HRA (IRAS project ID: 239197), Research and Development of University College London Hospitals NHS Foundation Trust, and the ethics committee at the London School of Hygiene and Tropical Medicine. All fieldnotes and interview transcripts were organised into folders in NVivo12. Analysis was conducted by all authors, who regularly discussed what was particularly striking or noteworthy, or had been especially emotive. Through these conversations we developed a joint feel for the data and identified further questions to explore. It was out of this process that the theme of place of death emerged. We shared our preliminary reflections on this topic with the palliative care teams during a workshop which consisted of a presentation and an interactive exercise which allowed the staff to discuss the significance of place, and the difficulties they had supporting patients to make decisions about where they wished to die and how to support this choice. Insights from this workshop enabled us to further develop our analytical argument around ‘placing work’.

Our emphasis on a particular aspect of current expectations of professional practice - namely, the increasing concern with patients’ preferred place of death - inevitably means that in this paper we focus primarily on the actions and reflections of staff. We do not seek to highlight differences between individual staff members, but rather the more general set of issues that they address as part of a team. However, since our general Practice Theory orientation ([Nicolini, 2012](#)) emphasises how specific practice always emerges from the interactions of multiple actors rather than simply the motivations or goals of an individual, we include patients in our findings where pertinent. Crucially, they are therefore not presented as passive recipients of professional practice, but instead as contributing actors – even when those contributions are to resist or divert the initial aims of the professional staff.

In the remainder of the paper we have consequently chosen to present a limited number of case studies in order to highlight some of the many diverse factors that interact with each other; those between professional staff, patients, and often patients’ relatives – but crucially, also the many material and environmental elements that often are highly significant to how a particular scenario unfolded. The cases, therefore, are not only illustrative of many other similar instances that we observed

during the course of our extensive fieldwork, but also serve as semi-bounded instances that enable us to foreground which factors, of the many different potential ones, played a primary role in considerations about the nature of place for people at the end of life. Combining all of these analytical processes, the result is a narrative-style presentation of our findings in line with concept of matter-ing, that inevitably combines descriptions of direct observations, which could be said to constitute representations of the ‘material’ world, with more interpretative assertions, which suggests some of contextual symbolic meanings which fashion those things as significant to the actors themselves.

### 3. Findings

In the following accounts, we illustrate the role of metrics in fixing patient place of care and death preferences, and secondly, ‘placing work’ – a term we coin to capture the work that goes into aligning place and matter in the context of end of life care. Whilst there were many examples within our fieldwork, we draw on a limited number to provide in-depth accounts of some of the scope of this placing work, and the tensions that staff must negotiate within it.

#### 3.1. Fixing preferences

In a Commissioner’s checklist for end of life care services in London, a focus on place of death is conveyed via the desired outcome that ‘Patients achieve their preferred place of care and preferred place of death’ (2016, p. 4). Not only does this wording include a slippage between ‘place of care’ and ‘place of death’, but the checklist reproduces the more general assumption that the majority of patients will wish to die at home, and that death rates in hospital will decrease accordingly. The apparently incongruous use of the word ‘achieve’ is noteworthy, in that it acknowledges the reality that satisfying a patient’s wishes often requires a great deal of input and support.

Often the palliative care teams try and fulfil this service expectation during their regular Multidisciplinary Team meetings (MDTMs). In recent years, the method to document a patient’s preference has shifted from a written form to an electronic record service called Coordinate My Care (CMC), so that it can be shared between different healthcare providers and avoid duplication. In these meetings, it became evident that although staff know they should officially record every patient’s preferences, it was often not (immediately) possible. Sometimes this is because they judged it was too early to raise the issue for a patient only just coming to terms with the fact they are going to die. But on other occasions patients are unwilling to talk about it until it proves absolutely necessary, or simply do not know what they want because they are unable to imagine how things might develop. Harry, a terminal cancer patient in his sixties who lived alone, put it as follows:

I’m no saint about these things, you know; the unpleasant things I will put off discussing until I need to discuss them ... Why not? There are things which everybody finds difficult to talk about, and mine really is about giving up control ...

In cases where a preference has yet to be documented, it is listed as an action point to be followed up swiftly by one of the team, unless more pressing clinical issues arise. Harry died in hospital without ever managing to talk about, and arrange, where he might want to die.

During fieldwork there was growing sense within the palliative care teams that recording this data was not just to reinforce patient-centred care, but for other organisational and financial purposes. Indeed, during the spring of 2019, the service manager overseeing both teams, Hugh, shared his prediction that the Preferred Place of Death, as recorded on the electronic system, would soon be used in audits to score the quality of the service. The implication of this was that the teams were likely to be under increased scrutiny whenever a death occurred in hospital. Recognising that it is often difficult to determine a patient’s

wishes, he was pragmatic about how such ‘data’ was recorded; as he explained after our workshop on place with the teams:

at some point, if you’re going to measure that, you have to make a mark in the sand, [and say:] ‘Right, it’s Wednesday. For you, today, hospice is the preferred place of death.’ They get to the hospice, we would then tick, and we think we’ve achieved that metric.

For Hugh, the growing requirement for staff to log a PPD can mean that sometimes they must make a decision on behalf of the patient. And significantly, he uses the notion of *achievement*, just like the wording in the formal policy document; but in this instance what is being achieved is not necessarily that patients lead a decision about where they may die, but rather that the demands of the ‘metric’ – and thereby policy – are fulfilled.

Through this bureaucratic process, *place* is reduced to stipulating a location without acknowledging the planning that might be involved, and that things may well change over time. The system not only sediments the decision, but also fixes a specific location. It is not surprising, therefore, that the team were frequently frustrated by this way of doing things. The lack of flexibility in the formal system is at odds with their experiences with people who are having to come to terms with the reality that their time is limited, and the oversimplification that both place and death can be addressed in such singular and absolute ways.

As a consequence, staff have to navigate a tension between managerial expectations that reproduce a straightforward notion of place of death, and their everyday experiences. Ongoing contact with patients, and often patients’ relatives, continually demands a dynamic, relational approach to care, meaning that where the most appropriate and comforting place for someone to die is often an open-ended and unresolvable concern.

In the following three illustrative cases we refer to ‘placing work’ as a form of matter-ing which is in direct contrast to the official requirements to record a PPD. It entails staff engaging with values, desires, conversations, and material things, through processes of negotiation, making practical rearrangements, letting go, and giving in. We analyse the ways in which certain symbolic and material elements associated with the idea of home, irrespective of actual place, are enlisted to create an environment that can support and comfort a patient who is coming to terms with the stark reality of dying.

### 3.2. Making a home for death and dying

June, an occupational therapist in the community team, made repeated visits to Carl’s residence in an attempt to ensure it was going to be suitable for his last few weeks. Carl, a quiet, humorous man in his late seventies, suffered from ischemic heart disease which made him rather weak and breathless. He also had been diagnosed with vascular dementia, although this was not the primary concern of Carl or his care team. He lived alone in a second-floor supported-living block in one of London’s more affluent neighbourhoods, and had been referred to the palliative care team ten months ago, when it was clear that there was no longer any possibility he would recover from his heart condition. And although Carl’s health was currently judged to be stable, he had previously deteriorated quite rapidly and this could happen again any time.

During fieldwork, June was on one of these visits. Carl was sat in a comfortable chair in his living room, surrounded by things of all kinds accumulated over the decades: shelves were piled up with novels, encyclopaedias and Greek mythology books; and there were countless black and white photos of his wife over the years. June had previously focused on reducing the risk of him falling or tripping over, which required emptying the space as much as possible. Together with Elisabeth, a professional carer who visited twice a week, they had set about clearing the living room and bedroom. Things that Carl wanted to keep were put in boxes, stacked behind the sofa. A central rug was taped down to the carpet beneath; June did not think this was a perfect

solution, but felt it was a reasonable compromise. She also had thrown away a lot of things in large black plastic bags.

The entire operation was about sifting through everything to establish which objects could be gotten rid of and which should be kept as they made the space feel like Carl’s home. This rapidly proved more complicated than simply sorting things into the two distinct categories: a great many objects carried stories and memories and helped Carl to hold on to his past, especially when his wife had still been alive. So while Carl openly acknowledged that he inhabited a disorderly space, it did not mean that simply jettisoning lots of things would suddenly make things clearer or feel more ordered. The ‘mess’, that from the professionals’ perspective constituted a risk of tripping, for Carl represented a source of stability and evidence of ties to a past that rapidly seemed to be disappearing. June and Elisabeth were sensitive to this and tried to find ways to preserve the ties Carl felt most acutely, whilst ensuring the space was safe and would be suitable for this last period of his life.

June explained that for this visit she was primarily concerned with how she might make space for the delivery of a hospital bed. As part of a commitment to enable patients spend their last days in their home, it is common for a range of medical equipment to be introduced to ensure they are safe and comfortable and do not have to be admitted to hospital. From beds, to commodes, to dialysis machines, the palliative care team have to coordinate with a wide number of service providers to address individual patient requirements. A hospital bed, which can be adjusted in multiple positions, would not only help Carl get on and off more easily as he becomes increasingly weak, but also those who look after him. So, working out how such a large object might fit in had become part of June’s efforts to avoid a hospital admission. But any underlying sense of urgency had to be balanced against the need not to impose changes too quickly.

In Carl’s small bedroom June pointed out the grab rails that had been fastened on the wall and the blocks placed underneath his old bed to make it higher. She was convinced now would be the right time to replace it with a hospital one. At least two chests of drawers would have to be emptied and removed to make enough space, and she would have to coordinate the furniture removal to ensure Carl did not temporarily go without a bed or get stuck with two for any time. But while a hospital bed would have clear practical advantages for Carl and those who care for him, a bed is also highly symbolic. Beds are, arguably, central to what makes a space a home, and often they are where people die (Cleeve et al., 2018; Van der Geest and Mommersteeg, 2006). The introduction of a hospital bed frequently comes with the stark awareness that it will be in the home until one’s death. So not only is it common for patients to resist having one until they fully accept they are close to dying, but professionals sometimes remark that it seems introducing a hospital bed can actually trigger someone’s death.

Clearly in order for equipment to be introduced, other things often need to be moved out. But the introduction of new objects which serve to mark out the sense of decline can affect how the home is then experienced. Frequently, new equipment sits uneasily alongside all the other things which form a web of memories and relationships that engender a sense of home. And often these new objects are perceived to be ugly, look institutional, and clash aesthetically with everything else that a person had collected over the years. Carl already found it difficult to get used to several of the adaptations that had been introduced into his home; he said he found the practical push frame with tea tray ‘a bit bulky’. And he initially resisted a bath lift – being ‘fiercely independent’, as June put it – only to later relent after he fell on one occasion, despite the adaptive handrails that had been installed. Hence the placing work June does involves much more than these kinds of logistics or corralling different external services; so much is about carefully supporting, negotiating, and working with Carl to ensure the changes do not feel like intrusions or disruptions. Beyond simply responding to his physical decline, the gradual, processual way in which June introduces the new objects has to be aligned with the symbolic; with Carl getting used to the fact he needed assistance, and that both his body and his surroundings

were inevitably changing.

### 3.3. Making the hospital for death and dying

Similar ongoing work to make a location suitable and meaningful for a patient in the last stage of their life also happens in hospital. Despite the policy emphasis on dying at home, the largest proportion of people in the UK still die in hospital, as in many other countries (Cohen et al., 2015; Office for National Statistics, 2020). Inpatients referred to palliative care stay on the busy hospital wards that have up to twelve beds in a bay. Lying in a standard bed with a side table, the only semblance of privacy is visual: a blue curtain that can be drawn around them.

Acknowledging the fact that such hospital spaces never feel like fitting places to die, the national SWAN (Sign, Words, Actions, Needs) programme supports all clinical staff to provide compassionate care to patients who are identified to be at the end of life (Nottingham University Hospitals NHS Trust, n.d.). The initiative encourages staff to 'create a comfortable environment to ensure families can spend time closely together in peaceful surroundings' (Nottingham Hospitals Charity, 2019). A swan symbol, placed near a patient's bed or on a door, not only indicates that they can be visited around the clock, but that activities such as giving the patient a manicure, or chatting about photographs to share memories and laughter, are encouraged. Family members may be given 'comfort packs' that contain toiletries for any overnight visits that they make. In contrast to the generic space around most hospital patients, these efforts attempt to transform the area around a dying patient into an environment that is more personal, comfortable and meaningful.

Susan was a woman in her early forties, who already had been a hospital inpatient on the oncology ward for several weeks. Once it was evident that she was soon going to die, the SWAN initiative was introduced. Because there was no side room on the oncology ward available, specialist palliative care nurse Anna arranged for Susan to be moved to the geriatric ward, where one was available. Anna told her colleagues during an MDTM that Susan's family really appreciated the room and had 'made it very lovely'. With Anna's encouragement, Susan's children had posted a sign on the door saying 'only come in if you bring in love', and they brought in personal items to make it 'more her own space'. These modest tokens served to establish a pocket of familiarity and individuality within the impersonal institutional environment.

When a side room became free on the oncology ward, the regular ward staff automatically made plans to move Susan there. But Anna intervened, arguing that Susan and her family would not want her to be moved now that they had settled where they were. The palliative team were all too aware that keeping Susan on the geriatric ward might mean the regular ward staff would find dealing with the situation distressing – Susan was so much younger than the end of life patients they usually cared for, and her children were still relatively little. So the team discussed at length ways they might be able to support the ward staff as well as how best to care for Anna and her family. This illustrates how the work of placing can involve supporting the other professionals around a dying patient, as well simply making the physical space around a patient feel more personal and comforting.

Notwithstanding all the attempts to turn hospital spaces into meaningful places, patients cannot stay for an indefinite period of time because beds are nearly always in short supply. So palliative care professionals are often called upon to help with the process of sending patients back home, or to a care home, or a hospice. They often feel conflicted about this; on the one hand, they may believe that the hospital is likely to be the best place for very ill patients to be – especially during a medical emergency. But they also recognize that being on a very busy hospital ward is usually not really the best environment for someone who is dying. So, depending of the prognosis, team members may talk to patients who have been there a while about going home, gently introducing them to the idea that somewhere else might be more suitable for their last stage of life.

During these delicately coordinated conversations, professionals have to deal with the fact that some patients have become quite settled in hospital and derive security from the institutional regimen. This was certainly the case for Giorgio, a patient in his early seventies with terminal cancer who had been admitted to the hospital after a fall at home. He lived alone, and had a history of mental health problems, including anxiety and depression. It had taken hours before he had been able to call an ambulance, all the while lying on top of a broom stick which had caused a large, dangerous pressure sore on his leg. Now, after staying two weeks in hospital for it to heal, he was deemed 'fit for discharge'. However, Giorgio was very anxious about going back home. Because the general ward staff interpreted this as him 'resisting' their efforts to help, specialist palliative care consultant Julia was approached to 'facilitate discharge planning'.

Palliative care consultant Julia was aware that discharge often becomes more difficult as time passes, especially for patients like Giorgio who had become particularly accustomed to the sense of safety in hospital. As she closed the curtain around Giorgio's bed, she reminded him of the support he had had before his fall, and what new arrangements would be introduced, including more frequent visits by community nurses. But Giorgio made it clear he felt the arrangements would not be enough, and he was particularly worried he might fall again. Home, for Giorgio, had become an unsafe, fearsome place. He fiercely rejected any of the alternatives suggested, such as a care home, saying he just wanted to stay on the ward. Julia acknowledged his concerns and told him she would make sure that he could stay another night, but that she had no choice but to come back the following day to start the discharge procedure. On the way to the next bay she acknowledged that this was probably not what the ward staff had hoped for, but that the extra night was the least thing she could do for Giorgio, particularly because he was 'not close enough' to dying to warrant a hospital stay. Maybe she would have better luck tomorrow, she murmured.

Giorgio's case illustrates an intractable contradiction that the palliative care staff have to deal with. If a dying patient has to be in hospital, then they will do everything they can to transform the space, even though possibilities to do this are limited. However, they also have another role – to ensure that only those patients who can be justified clinically to stay in hospital do so. This forces staff to draw on a very different set of criteria and values, and switch from being the patient's advocate to representatives of a health service that always has limited resources. In this way, placing work reveals inherent tensions between policy agendas, limited healthcare resources, and the professional commitments of staff to care of individual patients, which all converge during the apparently straightforward matter of helping decide where a patient might spend their last days.

### 3.4. Placing things in time as well as space

Although we have illustrated how the specific sites and the (re) organisation of material objects and practical arrangements are drawn on to help make a location suitable for a patient at the end of life, there are often important temporal aspects to this as well. The team try to ensure patients do not have fixed expectations and, in that way, might actually feel more in control; they often encapsulate this in the phrase, 'Hope for the best, and plan for the worst'. The most important thing, they all say, is to talk frankly about any plans, and provide a range of options for all the possible scenarios.

In this way, while a key aspect of 'placing work' is to make the present feel stable and secure, another is to make sure the future is not frightening and can be imagined as a place to 'be'. So, in addition to a concern over the physical environment, the staff routinely try and help patients, and often their relatives, conceive a future that nevertheless feels safe and familiar. In an interview, clinical nurse specialist Carla said:

we see this every day, and we know what [the patient's] journey will look like ..., but I don't think that a lot of people can. So, asking them to think about the future, and what they may want is quite abstract. Things change so much, and there's so many possibilities that could lead to someone needing to be in hospital. ...

Here, Carla expresses the struggle many terminally ill patients and family members have imagining any kind of future at all because their current experiences are just so all-encompassing. Thinking about the future will not only include addressing where they might wish to die, but also in a more abstract sense, trying to envisage the situation more generally. Carla acknowledges that ultimately it is impossible to know, because the specific nature of someone's death cannot be predicted. But the ability to situate themselves in the future is nevertheless a really important dimension to how many patients cope with things in the present.

Consultant Agnes recalled the case of a daughter whose elderly father had advanced dementia and an advanced stage of terminal cancer. Although the daughter had conveyed his wish to die at home on numerous occasions, an acute bleed episode compelled her to call for an ambulance. She had not wanted them to rush him to hospital, but simply deal with the emergency. However, because she did not possess an Advance Directive or Advance Refusal of Treatment form, the paramedics had no choice but to take him. Later on, when the father had returned home, Agnes and her consultant colleague Christoph decided to make a visit, to try and work out how to prevent a similar event from happening in the future.

During their conversation the daughter became quite distressed when she realised it would entail paperwork that stipulated that, in such an eventuality, her father should not be resuscitated. It was a future that she had not imagined. Agnes suspected that some of this distress might be related to the daughter's faith and the Islamic doctrine that is often interpreted to mean life must be preserved at all costs. 'She always thought she would just be able to say no', Agnes recalled. In order to resolve this, Agnes suggested the paperwork be completed, but that the daughter could decide whether to actually show it to a paramedic or not. The strategy would give her a sense of control in the present, yet not necessarily determine what might happen in the future.

This account illustrates the extent to which palliative care staff do their best to foster a sense of stability for patients and family members in the present, whilst ensuring they do not form an overly rigid idea of the future (although, as Agnes remarked, this strategy would not necessarily have been available to nurses as much as it was to two consultants due to structures that assign and back accountability for clinical decision making). The team regard helping a patient to place themselves, or relatives place a loved one, in the future as a crucial aspect of their caring role. It involves not only of coming to terms with dying but thinking through different likely scenarios – putting plans in place where possible, and where this is not, offering strategies to deal with not-knowing. Conveying this has to be done very cautiously, because it introduces an inherent ambiguity about what might happen which can rapidly spill over and undermine people's tentative ability to cope in the meantime.

#### 4. Discussion

As the requirement to record choices of place of death have become more formalised, they are increasingly part of a set of metrics used to monitor the quality of end of life care services (London Strategic Clinical Networks, 2016). Implementation of this quantitative approach undoubtedly can have value, as it is designed to ensure so-called difficult conversions are not simply avoided, and that care teams address how patients may leave hospital but still get the support they need. But formally recording the Preferred Place of Death, and using such registers in clinical performance reviews, risks closing down placing work as an integral aspect of the care delivered. Some of the more technological

processes being introduced to facilitate planning for a place of death – such as electronic records and advance decision documentation – make such flexibility even more difficult, as their very efficiency and standardisation fixes decisions permanently, thereby foreclosing the more ongoing and adaptive nature of the work we have described in this paper. In this way, care involved in and around such conversations, and placing work itself, get reduced to a few simple categories and check-boxes (Borgstrom and Walter, 2015).

In our study, palliative care professionals unsurprisingly felt frustrated by how the patient's preferred place of death is currently being documented and used as a crude measure of the quality of care. The simple category option not only fails to reflect the many different aspects of an individual patient case, but also the sense that even if a patient has stated a preference, this can often be contingent on a wide range of factors - from how their illness may progress, through to what kinds of assistance might be provided by support services and possibly their relatives. Both the space, and things within it, can be assessed as messy or problematic – either because they pose risks to the progressively vulnerable patients or because they take up space needed for equipment that increasingly becomes necessary. The resulting critique of a place of death tally resonates with those advocating a focus on the care provided instead of simply its location (Barclay and Arthur, 2008; Engelberg et al., 2010).

Key to our specific approach, however, has been an emphasis on processes and practices, rather than rigid and unambiguous categories. Instead of coupling the singular notion of death with an unproblematic idea of place, our long-term ethnographic fieldwork highlights how palliative care staff look after people who are in the process of *dying*, and as a consequence address the matter of where they might die as process as well. Contributing to the wider literature about the importance of carescapes (Bowlby, 2012), we have shown that, when thinking about place of death, what is considered fitting and what might be 'out of place' is often not clear, since both the dying patient and their environment are often in flux. Palliative care staff work to actively to keep decisions open because part of the process is an embracing of inherent uncertainty.

We consequently have put forward the idea of 'placing work' to describe the ongoing efforts of palliative care staff to ensure a dying person's environment feels as safe and meaningful to them as possible. Placing work challenges many of the assumptions built into policies that advocate fixing a Preferred Place of Death, which operate on static notion of 'the patient', the event of death (rather than process of dying) and the various place options that they might consider. In order to make a place suitable for dying, spaces often have to be altered not only materially, but also symbolically. Because the relationship between a person and their environment often changes, especially as their condition deteriorates (Gerber et al., 2019; MacArtney et al., 2015), this placing work routinely contrasts with the official, policy-led approaches that present 'place of death' as a singular, fixed category. Palliative care staff spend a great deal of time adjusting, adapting the environment by shifting things, people, and expectations, whilst always trying to keep options open.

Staff not only feel committed to supporting patients being able to change their preferences but also enable a degree of ambivalence – both in terms of whether a patient's home really will be the best place, and because what constitutes home can itself change. As others have similarly argued (Latimer and Munro, 2009; Lovatt, 2018; Pasveer et al., 2020), 'home' and 'homeliness' are neither guaranteed, nor limited to, the arrangements to people's dwellings. Instead, home is 'the result of a shifting arrangements that organize private and intimate relationships and 'stuff' in particular ways' (Ceci et al., 2020, p. 309). This is a crucial insight, as it opens up spaces other than individual's residence where people may wish to die.

But our examples also point to how the palliative care team are entangled with wider organisational logistics and priorities, whether they are in a patient's home or in hospital, and the many practicalities of

the health and social care systems they operate in. Collier and Broom put forward similar critiques about the policy focus on home as a desired place for death and the wider set of work that is required to enable it to manifest (2020). As a result, professionals have to continually shift between the static recording of place of death and the interactions that go into the placing work in their everyday interaction with patients and those close to them. The fact that the palliative care teams receive referrals from other teams or wards to facilitate placing work, such as discharge planning, suggests that they are considered better equipped to do this kind of work. There are several reasons why this may be, including that they have more time to talk to patients, that their holistic and multi-disciplinary approach enables them to take into account a wider range of factors, and because they are more skilled in dealing with and communicating uncertainty (Broom et al., 2015).

We suggest, however, that placing work may be a useful concept to make sense of the more widely distributed work that is required when making places suitable for care, and making places suitable for living as well as at the end of life. For instance, making a place 'homely' is an important aspect of the care in nursing homes (Fleming and Kydd, 2018; Lemos Dekker and Pols, 2020). Further research could be done to understand how people make sense of the moral implications of placing work (see also Stonington, 2012 for examples of the ethical frameworks used in different locations) and how placing work is distributed across people and teams.

Overall, we have drawn on the notion of placing work to highlight the ongoing work done by palliative care staff to align ever-shifting spaces, people, objects and time that make certain places symbolically-materially appropriate for dying. Whilst there is a policy and operational emphasis on patients choosing their place of death, which promotes home as the most usual preference, what is involved in placing work highlights how such places need to be *made* suitable for dying. The current focus on place, as a response to concern over the medicalisation of death, is not sufficient if place is operationalised non-socially, as a fixed entity. In such circumstances, it routinely becomes just another metric, devoid of precisely the things that the push to 'take place seriously' was originally intended to do.

Any sense of security, as well as meaningfulness, derives from a temporary alignment between the person, people around them and the material world. This is also often about aligning different people's perspectives about such matters, including those of the palliative care professionals. In doing so, palliative care professionals sometimes find themselves caught between attempting to manage organisational expectations and the on-going work of both caring for patients and their environments. This concern illustrates a more deep-rooted issue that we have explored in this paper: The increasing trend to make PPD a standard measure in documentation and audit trails not only means 'place' is operationalised as a self-evident static element, but becomes tied to an equivalent construction of death as an unambiguous, singular event. In other words, treating both place and death as fixed and definitive entities clashes with the central philosophy of contemporary end of life care, which not only emphasises that dying is always a process but also an inevitable part of life.

#### Credit author statement

Annelieke Driessen: Obtaining ethics approval, data-collection, analysis, conceptualisation, writing: original draft preparation, revising and editing, visualisation, project administration. Erica Borgstrom: Funding acquisition, obtaining ethics approval, analysis, conceptualisation, writing: original draft preparation, revising and editing, project administration. Simon Cohn: Funding acquisition, obtaining ethics approval, analysis, conceptualisation, writing: drafting, original draft preparation, revising and editing, project administration.

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