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Home death as a conditional ideal: ethnographic insights from an English hospital

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ABSTRACT

Advance care planning is a process that involves ascertaining and documenting a patient's preference for future care, especially in the context of end-of-life care. Based on an ethnographic study of advance care planning involving fieldwork in an English teaching hospital in 2018, this paper highlights how for healthcare staff, advance care planning is about more than patient preferences. Instead, for staff, advance care planning links to notions of how to achieve a good death, which many interpreted as ensuring patients can die at home. Within this logic, home death was conceived as a strived for ideal. Yet, staff acknowledged home deaths were not always possible, dependent on the availability and capability of home-based care and symptom management. As such, staff recognised a need for 'flexibility' with processes that may focus on ensuring a patient dies at home. Consequently, we interpret this as seeing home death as a conditional ideal. This builds on existing literature that outlines and challenges expectations of good death, home death and discussion of place of death, crucially adding a term – conditional ideal – by which to understand the nuance that exists between discourses of end-of-life care and how it unfolds for staff, patients, and families.

KEYWORDS

Home death; good death; advance care planning; end-of-life care; ethnography

Introduction

James was a patient within England's National Health Service (NHS), diagnosed with cancer seven months prior to meeting him. As he waited for his consultant to return to the clinic office, he said 'I just want to be able to watch television at home in my own chair, and when things get bad, be somewhere where they'll take care of me and my wife doesn't have to'. As the consultant re-entered the room, James directly asked how much time he had left. This question about prognosis developed into a conversation involving advance care planning (ACP), covering what care James would likely need and receive, who would care for him as his condition changed, and his place of care. The focus was on his end-of-life care and encapsulated the components of ACP. This article takes ACP as its starting point and discusses how the logic of ACP means staff focus on place of death,

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with home death as an ideal, as part of how they engage in providing end-of-life care. Yet, we show how staff also grapple with a tension: home being understood as an ideal, patients wanting to be at home, but often not actually wanting to die at home. We explore these tensions.

Advance care planning

Advance care planning (ACP) is advocated for in English end-of-life care policy (Department of Health, 2008; National Palliative and End-of-Life Care Partnership, 2015). Advance care planning is described as ‘a voluntary process of person-centred discussion between an individual and their care providers about their preferences and priorities for their future care’ (Universal Principles for Advance Care Planning, 2022, p. 4). It can involve multiple conversations about these issues, with the intention that preferences are documented and shared with care providers (and family/informal carers where relevant) to inform ongoing and future care provision (K. Thomas et al., 2017). Internationally, ACP differs in terms of process, documentation and legality but can come in the form of advance directives, living wills, a statement of preferences, as well as conversations that are drawn on in surrogate decision-making.

The process of ACP is thought to empower patients and those who care for them (Universal Principles for Advance Care Planning, 2022). Kaufman (2005, p. 226) has noted that treatment and care decisions make the question ‘How do I want to live the remainder of my life?’ pertinent for patients and those caring for them, inviting considerations about what is possible and desired in a context of medical interventions. For some, undertaking ACP initiates feelings of control and links to notions of a ‘good death’ (Andreassen et al., 2017; Carr, 2012). For health services, knowing a patient’s preferences can enable the organisation and management of care. As such, previous research has demonstrated how practices around ACP can focus primarily on the place of death (Borgstrom, 2015), with health services research aimed at demonstrating correlations between advance care planning and place of death (Dixon et al., 2019; Orlovic et al., 2020; Skorstengaard et al., 2020).

Considering the entanglement of ACP, good death, and home death

ACP has been a focus of research internationally, to the extent that an overview of systematic reviews exists (Jimenez et al., 2018). Existing research has focused on various elements, from implementation and efficacy (Cerulus et al., 2021; Houben et al., 2014) to staff and patient perspectives of ACP (Robinson et al., 2013; Zwakman et al., 2018). From a social science perspective, researchers have interrogated how ACP is done in practice and the potential unintended consequences of focusing on ACP in clinical practice (Borgstrom, 2015). Collectively, this research shows that ACP is not a single process or set of practices and that understanding local articulations and understandings of ACP provides insight into how ACP is being used by people and within a healthcare system and how that may (or may not) impact health and end-of-life care outcomes.

While ACP can be about a wide range of factors, from specific treatments to place of death, the focus on place is, in part, a legacy of how ACP is mobilised in English end-of-life policy discourse and implementation. While our focus in this paper is on England, ACP is

a feature of policy in all four nations in the UK (K. Thomas & Russell, 2023). English end-of-life care policy has been developing for over two decades. This policy draws on the philosophy and practice of palliative care, which itself has been influenced by the writings of people like Elizabeth Kubler-Ross and Cicely Saunders, who stressed the centrality of the dying person and their views. Such policy seeks to address expected demographic changes that can strain a national universal healthcare system whilst also seeking to improve the quality of care experienced by people (Borgstrom, 2016). One of the explicit intentions of such a policy is to ensure more people experience a 'good death', with policy advising that people be given the opportunity to express preferences about their end-of-life care (Borgstrom, 2020). The Preferred Priorities for Care document, which can be used as part of ACP with a prominent focus on place of care/death, is endorsed in national policy (Department of Health, 2008). Evidence about patient preferences for place of death is used within end-of-life care policy (see, for example, Higginson & Sen-Gupta, 2000 cited in Department of Health, 2008); 'home' is therefore emphasised in policy rhetoric as the preferred choice of 'place' for the end of life, encouraging people to go home during this period (Pollock, 2015). Policy discourses, therefore, are linking place of death with notions of good death.

Policy focus on place of death, and particularly 'home death', in relation to ACP has inspired a range of studies about these issues both in the UK and elsewhere. Place of death, however, fits into broader and older death studies of how the end of life is managed. Health services researchers have investigated correlations between ACP and place of death, in terms of achieving preferred place of death (e.g. Dixon et al., 2019) and in relation to emergency hospital admissions (Sakamoto et al., 2023). A different approach adopted by social scientists has asked what 'home' means to people (Visser, 2019). Collier and Broom (2020) highlight how in policy and palliative care, home is considered a place with great personal significance, with assumed ontological and material security. Research about the meanings of home at the end of life indicates that feeling safe is linked with a sense of feeling 'at home', even if the physical place is not one's residence (Collier et al., 2015). As Borgstrom (2020) has highlighted, policy discourse around place of death frames home as a place where someone is likely to be surrounded by family. The connection between home as preferred place of death, and the creation of 'homeness', often means that a 'good death' is conflated with being at home, and the relationship between the home and good death is often naturalised in the literature.

Several existing lines of arguments exist that challenge the 'neat' connection between home death and good death, and the role of ACP in driving either. For example, retrospective research about home deaths reveals a range of views on how 'appropriate' dying at home is, particularly from caregiver perspectives, and how this can impact one's experiences of the home space after death (Holdsworth, 2015; Jones et al., 1993; Teno et al., 2004). Such work establishes the assumption that home deaths are automatically evaluated by all as 'good' deaths. Additionally, research underpinned by a growing awareness of socio-economic inequalities has demonstrated that people are pragmatic and flexible about place of death, focusing more on comfort and companionship (Pollock et al., 2024). This ability to enable non-home locations to be sites of possible 'good deaths' is also present in how people attempt to make hospices and care homes 'home-like' to enable 'good deaths' (Ellis, 2010), with a focus on reducing the presence of medicalisation. Even in interventionist settings, people

engage in practices that enable them to blur the boundary between a medical-technical death and a 'natural' death, especially in contexts where 'dying gently' and without life support may be deemed to be preferred (Seymour, 1999, 2000). Some have taken a critical stance on the drive to increase home deaths as being more of a response to managing the cost of medicalised, in-patient dying when policy makers assume that dying at home is 'cheaper' (Pollock, 2015). Such arguments recognise that pressures on hospital capacity have encouraged local policies that promote moving people who are unable to be made 'better' out of hospitals into their own homes or care homes (Thwaites et al., 2015); a pressure that has intensified since the COVID-19 pandemic (BMA, 2025). Lastly, research considering social and cultural aspects also highlights how ACP is individual-centric but that care and decisions at the end of life can be family-centric (Tay et al., 2017; Zivkovic, 2018), which can influence where someone dies. Such research has also demonstrated how perceptions of 'good death' and the merits or risk of medicalisation at the end of life are culturally informed. So, while English end-of-life care policy connects ACP with enabling a person to experience a good death by being at home, various empirical studies and theorisations enable a recognition that this entanglement is not 'given' in all contexts and is worthy of further exploration.

In this article, we explore the ways that staff working with patients at the end of life, discussed ACP. We argue that the logic of ACP means that staff often focused on place of death (with home as the ideal) as a cornerstone of ACP and providing end-of-life care, even though there are multiple elements to EoL care and ACP. As such, considering the relational aspects of ACP and place of death is important. We explore the ways that 'home as ideal' and place of death became the primary concern in ACP.

Methods

This paper is based on research conducted by a local [health charity], an independent charity and statutory body developed as part of the remit for the 2012 health and Social Care Act for England and Wales. [The charity] engages with local health issues, seeking to ensure the voices of health seekers are heard through engagement and research. In 2017, the organisation sought to address an increased attention, on end-of-life care and ACP challenges. As part of this, Author 1, an anthropologist employed by [a health charity], was tasked with collecting data on how ACP was occurring in the local area. To do this, Author 1 used an ethnographic approach based on participant observation and interviews (Borgstrom, 2018). The focus was explicitly on ACP. Author 1 carried out the project and analysis; Author 2 acted as an academic affiliate and co-author. References to 'I' in the methods and data sections refer to Author 1; other names are pseudonyms. Ethics clearance from a Research and Ethics Committee (17/LO/1467) for research being conducted on an NHS site.

The study took place over six months at a hospital in southeast England from late 2017 to early 2018, involving field visits 3 days a week during this period. The hospital was chosen because [the health charity] had identified it as a site in which ACP was likely to be occurring within the region. This is because it had a well-established specialist palliative care team, training about ACP and end-of-life care for all staff members, procedures in place for engaging in ACP. Fieldwork was conducted in the palliative medicine and renal

clinics at the hospital; project stakeholders identified these as locations where ACP occurred. Posters were put in these locations to inform staff, patients, and visitors that research was occurring.

Hospital clinical-participants were informed of the research on multiple occasions and invited to be observed by Author 1 in their consultations with patients and/or during ward rounds. With consent of both the clinician and patient, almost 100 consultations were observed and nearly 100 ward rounds were attended with hospital staff. Author 1 worked with six medical staff over the fieldwork period, shadowing them during ward rounds, clinic consultations and meetings with patients and their families. This included 'chatting' with them in-between clinic patients or ward-rounds as observation interviews. Author 1 took notes during consultations and ward rounds, observing interactions between staff and patients; consultations and ward rounds were not audio-recorded. Informal interviews took place during rounds, between clinic appointments and in the doctors' locker rooms, and ten formal interviews, lasting up to 45 min, were audio-recorded with consent. Patients and their relatives were observed, with their consent, during ward rounds and in clinic consultations. As many were unwell, we decided not to do formal interviews and rather relied on observation of ward rounds and informal conversations to get 'impressions' of their thoughts and feelings relating to ACP.

The research was underpinned by an interpretivist framework (Geertz, 1973). Geertzian interpretivist analysis allows for the contextual and symbolic components of a social setting to be borne in mind when interpreting and analysing results. Due to our interpretivist approach, in which context was critical to the analysis, an inductive approach was used in which 'the researcher begins with an area of study and allows the theory to emerge from the data' (Strauss & Corbin, 1998). Bearing the context and socio-economic realities that come to bear on healthcare interpretivist analysis complemented with inductive method was useful because of the inductive analysis approaches that: 'primarily use detailed readings of raw data to derive concepts, themes, or a model through interpretations made from the raw data by a researcher' (C. Thomas, 2005). As the analysis was inductive, our theoretical underpinnings were not pre-determined and instead developed alongside our engagement with the data and considering the data in the wider context of, and academic discussions about, palliative and end-of-life care within the country. Inspired by political-economic framings of medical care, analysis developed to understand how political mandates for ACP, that link ACP to home deaths and healthcare savings, shape clinical practices and clinician's views of ACP, beyond what a patient's preference may or may not be.

Author 1 wrote up notes and transcribed interviews during the fieldwork. Initial analysis was inductive, with Author 1 using interpretative analysis, whereby the context in which events took place and what was said mattered (Geertz, 1973). Notes and transcriptions were coded weekly to draw out key terms used by participants: these terms were categorised into concepts and themes. When themes from a few days of fieldwork began to establish a pattern, Author 1 tailored interview questions to affirm whether themes were similar for other participants. We ensured against selectivity by thematising during fieldwork so that Author 1 could ask questions again to new participants as well as discuss findings with medical staff, allowing them to affirm or disagree. Author 1 conducted formal interviews with staff at the end of the fieldwork period to allow for some of our discussions to centre on findings. This approach was beneficial for

checking interpretations of the data, recognising both authors' positions as non-clinicians who were also not patients experiencing their own end-of-life care. A project report was produced for [the health charity] focusing on the challenges faced by patients and professionals when doing ACP, with the intention of providing recommendations for practice (reference removed for anonymity).

Findings

Our findings show that discussions of ACP often centred on (preferred) place of death. The concept of (planning for) 'going home' or 'being home' was a recurrent theme in conversations with professionals. Below, we examine how dying at home is considered an ideal within the logic of ACP as mobilised in the site, and the perceived challenges to being able to achieve this ideal.

Home death as presumed ideal

Over the course of fieldwork, a pattern revealed how medical staff linked the notions of 'good death', advance care planning, and where a person died. Staff felt that striving for a good death for the patient was crucial to their job and part of providing good end-of-life care. As shared and observed throughout the fieldwork, staff viewed planning for the end of life via ACP as a mechanism for facilitating a 'good death' for their patients, as it allowed for understanding what a patient wanted and organising what to focus on and where to care for them. The link, as internalised by the staff in this study, is that patient choice and expressed preferences about place of death are important, both for organising end-of-life care and also for ultimately achieving what (staff) perceive to be a 'good death' outcome. In this way, for the medical staff, the desire to provide a good death experience motivated them to enact the organising of the end of life for their patients, via ACP conversations and follow-on actions, and this included organising where someone would die.

Consequently, home as an ideal place to die facilitated through ACP was a recurring theme throughout the research. For some staff, home was presumed to be a default ideal. For example, they either commented on how patients declared that they 'want to go home' (also observed during fieldwork) or how they themselves predicted that they would prefer not to be in the hospital environment at the end of their lives. As such, home was positioned as an ideal place because of patient 'choice', either as expressed or imagined. Since home was viewed as an ideal, staff declared that they were willing to make an extra effort to 'achieve' the preferred place of death, looking to accelerate discharge processes and liaise with community services for home-based care. The default of their logic, then, is that dying at home, which could be expressed as a person's preference, enables a 'good death'.

When patients challenge the palliative care staff logic of home as the default choice

While staff expressed a particular logic about good death and home as an ideal place for death and oriented their work with patients around facilitating advance care planning and discharge home, during fieldwork, there were instances that indicated that this logic

is not always unproblematic and could be challenged. This was apparent in the moments that people may not always want to choose (where to die) or that they may have other preferences, and that end-of-life care in the home environment may not always be possible or appropriate. The following sections illustrate this in more detail.

During the study, it was routinely observed that staff presumed patients would want to be discharged and be at home to die. When someone expressed a different choice, or even declined to make a decision about where they would prefer to die, staff experienced this as ‘challenging’ and they sought to make sense of an ‘unusual choice’. For Margaret, despite her 20 years of experience as a palliative care consultant and local expert lead for ACP, she was surprised by a non-typical choice. She sought to understand her patients closely, both through what she asked them and how she would position herself when talking to them, bending down to meet their eye level. Margaret remarked one day, how she made sense of when patients chose to stay in the hospital:

... for some people the default of staying in hospital is actually ‘I don’t have to make any other decisions’. But actually, that doesn’t necessarily mean it’s positive to stay in hospital, sometimes it’s because making any other decision is difficult. And actually, being in hospital generally for most people is not a good thing it’s busy, it’s not a home environment ... when some people say I’ll just stay in hospital it’s not because they actually want to be in hospital, they might want to come back in when they are very sick because they feel confident in the nursing care or the environment. But on a longer-term basis, it’s about the difficulty making other decisions. ...

She viewed the patient’s wishes to stay in the hospital, not as decisions – or choices – but as a representation of a lack of action and decision-making on the patient’s behalf. This framing illustrates how powerful the logic of ACP/choice and home as the preferred place of death can be for the staff, that when someone may opt for a location other than home it is not recognised as a legitimate expression of preference. Her comments also illustrate how the hospital is perceived to be not a good place for the dying person over time, contrasting to home as a perceived ultimate ‘better’ place, even when identifying hospital as a place where patients actively seek care. Margaret’s language was careful not to be overly generalising, speaking of ‘some’ and noting when someone is ‘very sick’ that, they may seek out hospital care; she was also not judgemental, outrightly claiming the preference or actions as ‘wrong’.

Another example of how ingrained the notion of home as the presumed default for the preferred place of death was expressed by the registrar when he was reflecting on a previous experience in a hospice:

I think that there are some people within the palliative care profession that find that hard to accept [that people may want to die somewhere other than home], I remember asking ... someone this question where would you like to die? And I was so accustomed to hearing home or hospice that when someone said, ‘I’d like to be in the hospital’, I almost did a double take. And the nurse who was with me afterwards asked me, ‘do you think he’s a bit confused?’

Isn’t it crazy that that’s the reaction, he must be confused because he wants to die in hospital? But actually, it is completely reasonable that someone who is very symptomatic, or they’ve got specific needs, then it may well be the right place to be’.

This example shows that even when a patient ‘actively’ expresses a desire to be in hospital when dying, the staff find this difficult to believe and instead question the

legitimacy of the person's decision-making capacity. The registrar's remarks illustrate that he recognised that this reaction was perhaps questionable and indeed rooted in palliative care ways of understanding place of death; however, his attempt to understand the decision is framed in terms of symptom and needs management. In this way, the choice of the hospital as a potential preferred place of death is only 'legitimate' in the context of (medical) need. Conversations like this with the staff illustrate, therefore, that at times they recognised that there may be limitations to what can be provided at home.

Limitations that can impact the perceived ideal of home deaths

During the fieldwork, observations showed how medical staff actively worked to enable people to die at home, facilitated through ACP and discharges, but there was an acknowledgement about the complexities of this. Whilst the above examples pointed to staff recognising clinical need and symptom management, staff also realised the impact of care on families and the practicalities of this in home environments. To illustrate this, we draw on an extended account that stemmed from an observation of a ward round with Margaret (the palliative care consultant, mentioned above) and her visit with David and his family.

David had been in the hospital for some time with complications linked to his terminal illness. He was known to Margaret, and they had regular conversations during ward rounds. During this ward round, David's son and daughter were both visiting and stood near their father, keen to hear what the doctor had to say. As was her style, Margaret got on her knees to be level with David as he lay in the bed. The conversation started with an update on how he was feeling that day and moved on to a discussion about 'getting home'. David explained he wanted to be at home but because of his condition, he recognised it was becoming increasingly hard to manage at home as he was in pain and struggled to move. There were concerns about how he would cope and who would be there for him. Margaret listened sympathetically and did not suggest a decision about discharge needed to be made immediately.

After the ward round, David's son asked to speak with Margaret away from the bedside. The son and daughter were led to the 'family room' in the ward. The family were worried about their father's condition. Margaret spoke about how David's condition was becoming more severe. She indicated that 'going home' seemed unlikely, given the level of support he needed and the projected progression of his condition. The consensus in the room was that home may not be the best place, and David would stay in hospital.

In a later interview with Margaret, we spoke about the limitations of home. She said:

I think that for some people, [going home is good]. But for some people it isn't; impact on family. Because actually we can't provide, or its very unusual to be able to provide 24-hour professional care for someone at home. So, it does place significant burden on family and carers, whether we like it or not, and patients are worried about that. As people get sicker, as people get more experience of death and dying, people with a close personal experience of death and dying are less likely to choose home. And then if you look at patients, so those who actually are sick, where they want to be its comes about 7 or 8th in the list of priorities. Really getting good symptom control, and not being a burden to others comes up top. So, people

make their place choices around where they can meet those other needs and that's not necessarily at home.

Margaret's account and her interaction with David on a ward round indicate that home was understood as an ideal, and is often the default 'starting point' in ACP discussions, but that one's condition and the potential burden of care could complicate whether home remained an ideal. Since it could be difficult to (clinically) provide what a patient needed at home in some circumstances, it was understood that home could be an undesirable place for a dying person, and for their family who are responsible for caring for them. The ideal of home, naturalised in ACP, was made complex when factors of symptom control, medical condition, and relational aspects (family) came to bear on decision-making.

A similar example was observed in the case of Andrew. I met Andrew three times during ward rounds: the consultant would ask how he was feeling, and each time, he responded that he was desperate to go home. Every time he insistently queried, with palpable frustration, why he was not home yet. During the second conversation I observed, the consultant said they were still looking for appropriate care equipment to be delivered to his house. After the ward round, the consultant explained to me that Andrew's daughter was, in fact, the cause of the delay: she was reticent about taking on caring for him without formal support structures in place. This was more than just the equipment in the house, but also additional care staff and knowledge of how to secure support if his care needs escalated. Since the hospital staff were unable to quickly implement this, as it relied on a range of other services, the discharge was 'delayed'. However, staff also tactfully had to ensure these concerns and delays did not strain familial relations, being careful with claiming that the cause of the delay was practical rather than relational, while also trying to reassure family that support could be provided.

Yet, the limits of home as an ideal place could also be understood by patients. While this was not always openly acknowledged by all participants in the study, here is an example of how staff could understand home as a 'less desirable' place for dying and death when they recognised how patients may feel 'safe' in hospital settings and when patients openly acknowledge that they do not want to put their family in the position of caring for them. A renal nurse specialising in palliative care, Millie, was interviewed during fieldwork as she worked regularly with patients who were making plans for end-of-life care. This was because for many of the renal patients, their condition, while not terminal, was life-limiting. When asked directly whether home is 'always the best place for people', she said:

That's what we presume, everyone wants to be at home, but in my experience especially looking after renal patients, they often want to go where they feel safe. Because we are almost like a home from home to some extent, they see us more than they do their own families sometimes, and sometimes their preferred place of care would be the ward. Because they feel safe there. There is one guy in particular that I remember. He was adamant about the fact he didn't want to go home, because he had nursed his own wife and she died and he was now, he had another partner. And he did not want his partner to go through what he had been through.

Millie saw patients who came to hospital for haemodialysis 3 days a week for 4-hour stretches for years. I witnessed Millie's familiarity with patients as I walked through the renal ward: patients waved and greeted her, and she greeted many of them by name.

A sense of 'knowing one another', even if in reality the relationship was still a patient-staff professional one, perhaps accounted for how Millie described hospital as being 'home from home' for some. It also established a clear, caring relationship – hospital as a 'safe' place to receive care from familiar people.

The accounts above indicate that dying at home is not always associated with a positive experience, especially for family members. Staff's ability to recognise the limits of the home as an ideal place for dying, due primarily to the impact of caring, problematises the immediate connection in the logic of 'home death' as a 'good death'. The way staff take these limits on board, without undermining their ultimate logic, is by delaying discharge, collaborating with other services to increase home-based care, and talking about hospital as a 'safe' space (rather than 'best' or 'ideal'). In this way, remaining in hospital while dying can be presented as a potential possibility and the practices of ACP can still be enacted. This approach, however, requires staff to appreciate a sense of flexibility, which is what we explore further in the next section.

An ideal that requires flexibility

Staff talked about the notion of flexibility in the context of realising ACP and 'good death', especially in the context of where someone died. In their view, the need for flexibility included limitations around care. It could also be related to their view that the last few days of life 'matter' and enabled them to advocate for and put arrangements in place for particular types or locations of care. In this section, we explore in more detail how the concept of flexibility was mobilised by staff in relation to the ideal of home death.

Greg, another doctor interviewed, talked about the need for flexibility in terms of being prepared that realising the ideal of home death is not possible, as illustrated in this interview:

A1: do you think that home is usually the best place for people?

G: I think it's quite a reasonable expectation. I think it's very context dependent what we say. Of course, we do our very best, if we can keep you at home, we try our very best. As we get towards end of life, their care needs increase significantly, so do they have appropriate familial support, spouse, children, other relatives? We have involvement with the community hospice team, so I think its absolutely achievable. However, we always would say we always have to be prepared for the potential that it's not possible.

A1: but its actually about sometimes having the ideas in place that you at least feel a little bit in control.

G: Absolutely, what we don't want is for it to be too regimented, there has to be flexibility there and understanding that things change. They can deteriorate significantly, and that's where you have that kind of difficult area where you could have done the best planning ever, you've got your preferred place of care all written up and signed, and your DNACPR written. But unfortunately, things change, and then it [ACP] goes out the window. So, one must never forget the flexibility there. Its eminently changeable. Or suddenly go, you know actually, I'm very worried about the stresses on my loved ones, they can't look after me at home.

In Greg's account, home was the best place for the end of life; he spoke of it as an 'achievable' event, indicating a goal orientation towards death at home. It is assumed that being at home is what everyone wants. Yet he recognised that plans may need to change.

Although not explicitly stated in these scenarios, hospital is indicated as a potential alternative. Greg's account of planning for end of life aligns with Margaret and Millie's understanding that dying at home was an ideal that required flexibility. Flexibility in this context was operationalised to do the work of allowing for 'Plan B'. Staff had internalised the political-economic imperative to send people home, and understood home as ideal. Yet, the changeability of contexts meant that while the ideal of home needed to be maintained, flexibility offered a method for framing changes in plans as being adaptations rather than failures. Medical staff thus worked with sets of ideals (often instantiated by policy, such as ACP) while also acknowledging and working with limits in their work. The clinicians had naturalised the policy discourse on home as best but because of the realities of dying and its associated needs and care, 'flexibility' was operationalised to account for the benefits and necessities of being in hospital. This is congruent with other research which has found how biomedical discourses and guidance influence how healthcare workers practice (Bontemps-Hommen et al., 2020) whilst still allowing for clinical discretion (Dumble et al., 2022).

So far, we have discussed how this notion of flexibility was mobilised to recognise the potential 'limits' to realising an ideal of home death, especially in the context of justifying why a patient may be in hospital. Sometimes, staff used the concept to argue for changing staff and (hospital) procedures to enable someone to be discharged home. This is evident in a discussion with Miranda, a renal consultant.

As one of the senior consultants in a short-staffed renal department, Miranda was usually the doctor at clinic sessions I attended over the six-month fieldwork period. She spoke about her weekly experiences between patient consultations and informally interviewing her regularly was possible. In one interview, she spoke about caring needs and resources available at home.

M: I think in an ideal world it would be good to be home, but not everyone has the resources and people to care for them. But in a society with restrictions, its not easy for people to access all these services no matter how, uh, it should be, but how it is in reality, they do not equate sometimes. So it is very difficult. Also, some people need more nursing care and the family aren't able to provide that sort of care even with support and then perhaps home isn't the right place. Depending on their symptoms, what's manageable at home. You need the right people in the right place at the right time. But obviously 24-hour care isn't always an option and weekends can be very difficult if they feel isolated on their own if the family member is getting worse and they're not managing symptoms and they can't get hold of the Macmillan team (cancer support) who often provide palliative and end-of-life care in community settings) and they get stuck and you can understand why they call the ambulance. But I think if you've got someone on the ward and they want to go home, you do your utmost to get them home – they've got a short finite time let's make their last few days as comfortable as possible, come on let's break through the red tape because you know it can be done if you make a fuss.

Miranda's discussion resonates with the previous examples – the presence of the home death as an ideal place and recognition of potential limitations around care and symptom management. The ideal of home death as a good death is acknowledged as not being the easiest option. And yet, rather than arguing for those limitations to be a reason to be flexible around the ideal, and enable someone to be in hospital, she stresses how the end-of-life context can legitimate a demand for care and support in the home. Flexibility is,

therefore, about the practices and policies that are ‘adhered’ to, not about the place (of death).

What these conversations with staff and extended observations revealed is that there is a difference (and tension) between planning to be at home, wanting to die at home (or caring for someone dying at home), and home actually being the best place for people. The dying process makes ‘going home’ a complicated wish and experience. Throughout the fieldwork, most of the patients observed had months and weeks left rather than years. Staff assumed they wanted to die at home, and many did indeed express this preference when directly asked. The stages of illness, however, play a significant role in whether or not that remains a wish for people and whether it is the ‘best’ or ‘safe’ option. Understanding this, flexibility is unofficially built into the ways doctors engage with planning, patients and their families, as well as other services. Although the logic is that home death is the ideal, the recognition of limitations and the need for flexibility illustrate that it is understood as a ‘conditional’ ideal.

Discussion: home death as a conditional ideal

Existing literature illustrates that death is not a timeless, universal, or problem-free concept or event (Borgstrom, 2020; Kuljić, 2016), and this paper demonstrates how healthcare staff can conflate practices of ACP with seeking to enable a good death, further conflating ‘good death’ with dying at home. The findings resonate with Pollock’s previous observations that in England, ‘home’ is assumed to be people’s preferred place of care at the end of life (although data about home death as presumed preference has been challenged, see Hoare et al., 2015), presumed to be the most ‘logical place’ and cheapest, and is understood to be a feature of what it means to define a good death (Pollock, 2015). In our study, for staff, their logic is that home death is an ideal – the view that it is an ideal is supported both by what staff think makes for a ‘good death’ environment as well as hearing that (many) patients want to be at home. This presents a tension in the findings in which clinicians frame home death as a good death, while patients largely preferred to be at home, although not necessarily actually dying at home. The realities of dying were recognised by staff and could be used as reasons for a patient to be in hospital. However, rarely did the staff explicitly say that hospital deaths could be ‘good’; they were always considered a compromise. As such, we argue that home deaths are perceived as a conditional ideal – an ideal strived for, supported by practices like ACP, but conditional, based on the ability and availability of care and symptom management in the home environment. While the initial aim of the study was to focus on advance care planning, the observations and conversations in the field illustrated that advance care planning was part of a larger logic and staff focus on the place of death. This links with existing research that has shown how advance care planning (discussion and documents) can (inadvertently) focus on preferred place of death (Borgstrom, 2015).

The findings resonate with existing literature that evidences the difficulties of dying at home (Wahid et al., 2017). The findings also support previous research that demonstrates that for some patients, especially in the context of ongoing acute care, hospitals feel safer and are their preferred place of death (Reyniers et al., 2014). Other studies about place of death have illustrated how staff actively craft or make ‘suitable’ places for dying and death

(Driessen et al., 2021); this paper adds to this research by analytically highlighting the notion of a 'conditional ideal' as well as the conditions that are considered by staff to be important.

At the time of data collection, ACP was being locally and nationally promoted as a way to reduce the economic cost of end-of-life care by improving the organisation of care provision and by reducing the amount of (presumed more expensive) in-hospital care at the very end of life. Yet, Bardsley and Georghiou (2014) point out how difficult it is to capture the true costs of care for the dying. They note that high hospital costs are often due to unplanned admissions, rather than people staying in hospital to die, and that it is difficult to cost the care provided by family/friends/informal carers. Reading their work in relation to ours raises questions to what extent policymakers (and healthcare staff) should presume that the home death ideal underpinned by ACP is of economic benefit.

In addition to the economic argument, it has been noted that a move to support deaths in the home environment is part of a wider social movement to de-medicalise death. The rise of hospice and palliative care is rooted in an attempt to de-medicalise dying, although this has been challenged (Borgstrom & Visser, 2025). Seymour notes that, within England, there can be a perceived binary between a medicalised death and a 'natural' death, and that effort is made to make hospital deaths seem 'natural' (Seymour, 2000). Whilst the participants in this study did not use the terminology of 'medical' or 'natural', their discussions about home as ideal and how symptom and care management challenges this point to an understanding of the home environment as being less medically oriented.

Since the fieldwork was conducted primarily within the hospital, and with staff who were generally supportive of ACP and end-of-life care, additional research is warranted to see if such strong ideals about home death and its conditionality apply in other contexts. Since clinicians acted as gatekeepers for patient-participants, it is unknown what other patients thought about ACP and end-of-life care. Author 1's position as a non-clinician meant she could reassure patient-participants that consenting (or not) to the study would not impact their clinical care. Ethnographic approach enabled Author 1 to see how ACP is done in practice and how the logic of home death as an ideal is created and enacted: to ask questions about people's assumptions, drawing on the observations and conversations to both check understandings and explore potential interpretations. Moreover, since the rate of home deaths has increased in the UK and other countries since the COVID-19 pandemic (Lopes et al., 2024), it would be beneficial to examine in what ways the 'conditional ideal' (including what conditions) is shaping who dies where and when.

Conclusion

As a conclusion, it is worth noting that there is a tension in the different ways of framing policy's structuring of care. While the connection and interrelatedness of the political-economy of care and how the logic of home informs and is naturalised in medical settings, healthcare staff can conflate practices of ACP with seeking to enable a good death that is conflated with dying at home. The logic, as internalised by the staff in this study, is that

patient choice and expressed preferences about place of death are important, both for organising end-of-life care but also for ultimately achieving what staff perceive to be a 'good death' outcome. This generated a desire to be committed to the 'ideal' of home death. Staff recognised that the ideal was not always achievable, arguing for flexibility. As a practice, flexibility was operationalised as a mode for explaining patient situations that did not fit the policy and procedures. Importantly, it was these ACP policies that were framed as requiring flexibility rather than home as an ideal overall that needed to be adapted.

Disclosure statement

No potential conflict of interest was reported by the author(s).

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