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The ideal and the real: Patient and bereaved family caregiver perspectives on the significance of place of death

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ABSTRACT
Home has become established as the preferred place of death within health policy and practice in the UK and internationally. However, growing awareness of the structured inequalities underpinning end-of-life care and the challenges for family members undertaking care at home raise questions about the nature of patient and public preferences and priorities regarding place of death and the feasibility of home management of the complex care needs at the end-of-life. This paper presents findings from a qualitative study of 12 patients' and 34 bereaved family caregivers' perspectives and priorities regarding place of death. Participants expressed complex and nuanced accounts in which place of death was not afforded an overarching priority. The study findings point to public pragmatism and flexibility in relation to place of death, and the misalignment of current policy with public priorities that are predominantly for comfort and companionship at the end-of-life, regardless of place.

Introduction

Supporting patients to die at home is a policy priority and a marker of good quality end-of-life care in the UK and internationally (Cohen & Gott, 2015; Department of Health, 2008, 2016; Driessen et al., 2021; Hoare et al., 2022; The Choice in End of Life Care Programme Board, 2015). Home is idealized as a place of great personal significance, material, and ontological security (Collier & Broom, 2021; Exley & Allen, 2007). It is assumed to be where most people would prefer to die, and to provide an environment which will enable them to experience "a good death" (Collier & Broom, 2021; The Choice in End of Life Care Programme Board, 2015). The commitment to home derives from resistance to the medicalization of death in the middle decades of the 20th century when the majority of deaths occurred in hospital (Lofland, 2019). A distinctive ideology of "the good death" was nurtured within the hospice movement from the 1960s and the subsequent development of palliative care as a medical specialty in 1987 (Clark & Seymour, 1999; Doyle, 2005). Dying at home is assumed to be cheaper than in hospital. However, the evidence to support this is not strong, as well as being hard to establish, particularly if the direct and indirect costs to family caregivers are considered (Gardiner et al., 2014; Imison et al., 2017; Luta et al., 2021; Milligan, 2016; Robinson et al., 2016). Nevertheless, the concern to contain the rapidly rising costs of end-of-life care provides a strong incentive for the encouragement of death at home. Hospital has become demonized as a cold, institutional, medicalized environment, where patients risk prolonged and futile treatment, against their preferences for receiving conservative palliative care and a comfortable and dignified death (Brereton et al., 2012; Robinson et al., 2016).

Between 2004 and 2016, the percentage of hospital deaths in the UK fell from 57.9% to 48.1%. Nearly a quarter (22.9%) occurred at home with 21.2% in residential care settings and 4.5% in hospice (Bone et al., 2018; Public Health England, 2020). Approximately equal numbers of deaths occurred in patients' usual place of residence (home or residential care) as in hospital (Nuffield Trust, 2021). However, place of death is determined by many factors, including age, diagnosis, ethnicity, location, socio-economic status, cause of death, and most critically, the availability of

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family support (Funk et al., 2010; Gomes & Higginson, 2006; Hoare et al., 2019; Sleeman et al., 2022; Turner & Flemming, 2019; Wahid et al., 2018). The regional variation and inequity in access to home deaths throughout the UK belies the rhetoric about place of death being a realizable "choice" (Barratt et al., 2017; Dixon et al., 2015; Nuffield Trust, 2021; Teggi, 2020).

Recent research also challenges perceptions of hospital admissions for patients close to the end-of-life as inappropriate, preventable, unwelcome, or avoidable (ONS, 2015; Papavasiliou et al., 2021). It has highlighted that at times hospitals are the only place where adequate care can be available (Gott et al., 2019; Hoare et al., 2019; Robinson et al., 2015). Moreover, patient and family assessment of end-of-life care in hospital is often reported to be positive (Gott et al., 2019; McKeown et al., 2010; ONS, 2015; Robinson et al., 2016). The stereotypical and simplistic opposition between home and hospital conveniently overlooks the significance of residential care and nursing homes as a place of death, and the increasing importance they will assume in future as an aging population experiences high rates of neurodegenerative disease and frailty (Teggi, 2020). It is debatable whether institutional settings such as care or nursing homes, although a "usual place of residence" constitute "home" in that it might not be an active, positive "choice" of place. Indeed, care homes are reported to be actively non-preferred (Calanzani et al., 2014; Hanratty et al., 2013).

While home may be their preferred place, many dying people strongly wish to avoid burdening family members with their care. This is one reason why institutional care might, in practice, come to be preferred to home. In parallel, there is literature about carer apprehension about their ability to meet the demands of care which materialize, and about failure to cope as an important reason for the transition from home to institutional care. Indeed, (Coe, 2020) questions why death at home has come to be seen as most desirable, given that it frequently poses great difficulties for family carers (Benson et al., 2018; Exley & Allen, 2007; Funk et al., 2010; Gerber et al., 2019; Milligan et al., 2016; Payne et al., 2015; Robinson et al., 2016). Carers report that they do not receive the quality or availability of care necessary to support a good death at home (Coe, 2020; Payne et al., 2015; Pollock et al., 2021; Wahid et al., 2018). In these circumstances, home ceases to provide a safe, secure environment and institutional settings may come to be seen as a better option where patients can receive more skilled, effective, and available care (Dying Matters, 2021; Hoare et al., 2019; MacArtney et al., 2016; Papavasiliou et al., 2021; Robinson et al., 2015). Home may only be valued as a place of death provided the family has adequate resources (material, financial and social) and professional health care available, especially in relation to adequate pain relief and symptom control (Hoare et al., 2015; Pollock et al., 2021). However, in the UK and internationally, health policy continues to perpetuate the markedly ethnocentric and middle-class ideology of the 'death positivity' movement and its idealization of death at home (Lofland, 2019; Pollock & Seymour, 2018).

Despite the intense promotion of the desirability of death at home, there is little evidence about patient and public perspectives of place of death and their experience of dying in different settings (Leemans et al., 2012; Islam et al., 2021). Nor is it clear how the views of the general public compare with the experience of dying patients and their families (Hoare et al., 2015). Policy has been developed and implemented by professional groups with little input from public perspectives and experience. Previous surveys indicating a majority support for home as the preferred place have been criticized for shortcomings in method and design, leading to a questioning of the evidence on which this view has traditionally been based (Hoare et al., 2015; 2022; Pollock, 2015). Qualitative evidence indicates that people exhibit a more complex and nuanced response in considering issues to do with place of death and end-of-life care; *place* is not afforded an overarching preference or priority (Benson et al., 2018; Gerber et al., 2019; Gott et al., 2004; Hoare et al., 2015; Islam et al., 2021; Milligan et al., 2016). Being comfortable and free from pain is consistently reported to be the greatest priority for most people (Islam et al., 2021; MacArtney et al., 2016; Robinson et al., 2016; Waghorn et al., 2011; Wood & Salter, 2013). However, pain is expected or experienced to be less well controlled in the domestic rather than an institutional setting (Gerber et al., 2019; ONS, 2015). People perceive that they are unlikely to have choice or control over the circumstances of their dying (Borgstrom, 2015; Dying Matters, 2021; Hansford et al., 2022). Where preference is voiced, this is often for hospice (Agar et al., 2008; Thomas et al., 2004). However, death in hospice is a realizable option for a small minority of dying persons and remains predominantly oriented to those affected by cancer (Hoare et al., 2015; Public Health England, 2020; Sleeman et al., 2016).

Greater knowledge and understanding of patient and public perspectives about place of death, and their experiences of supporting dying patients in different care settings, is a prerequisite for developing policy and services that are truly patient centered and responsive to expressed rather than professionally defined needs (Robinson et al., 2016). This paper explores the perspectives of bereaved family caregivers (BFCGs) and terminally ill patients about their preferences for place of death and the relative importance of place compared with other factors such as symptom control and carer burden. The findings reveal the tentative, shifting, and pragmatic nature of participants' thoughts and preferences for place of death. They highlight the distance between participants' real- world experience and the widespread assumptions about public preferences and idealization of home as the preferred place of death on which current end of life care policy is based.

Methods

Design

Qualitative interviews with BFCGs and terminally ill patients which formed part of a mixed methods study of public understanding and experience of death and dying. A topic guide was used to ensure consistency of the core topics to be discussed. However, the interviews were informal, flexible, and responsive to the issues and concerns which participants considered to be of greatest significance to their experience. Patient interviews began with an open question about the patient's illness, and included their understanding of prognosis, experience of care and support from professional services and family members, anticipation of the future, preferences for end of life, perspectives on the options thought likely to be available, and whether they had undertaken any preparation for the future including Advance Care Planning. Interviews with BFCGs asked about participants' experience of the death of one or more family members or friends, their involvement in supporting and caring for these individuals prior to their death, and how these experiences shaped their own perspectives and expectations of death and dying. All participants were asked if they were familiar with the idea of "the good death" and what they felt about this.

Recruitment and participants

Twenty-six BFCGs were recruited through a range of media including twitter, Facebook, and in local and national organization newsletters and magazines. A further eight BFCG participants and 12 patients were recruited through staff of four local hospices. Patients were eligible to take part in the study if they were over 18, fluent English speakers, had capacity to consent, were aware of the terminal nature of their illness and limited prognosis, and willing to talk about, and reflect on, this experience and their goals and values for future care. BFCGS recruited through the hospices were identified by staff as carers who had experienced bereavement at least eight weeks previously. Eligible patients and BFCGs were given or sent an information pack and invited to contact the research team directly, via hospice staff, or by returning a reply slip, if they were interested in taking part. The information sheet asked potential participants to consider carefully how they might feel discussing issues relating to death and dying before agreeing to take part. Participants were assured that taking part was entirely voluntary and that they could pause or end interviews and withdraw from the study at any time. Interviews were conducted by experienced qualitative researchers mindful of the need for sensitivity and vigilance in detecting participant distress.

Interviews were conducted by three female researchers with academic backgrounds in sociology and social anthropology. A topic guide provided an aide memoire and means of loosely structuring a discussion which was led by participants' experience and the issues they considered to be of greatest significance and concern. Written or recorded consent was obtained from all participants prior to the start of the interview. All participants are referred to by pseudonyms. For ease of reference BFCGs are designated by name (John Smith) and patients by title (Mr Jones).

Ethical approval

The study received approval from the University of Nottingham Faculty of Medicine and Health Sciences Research Ethics Committee (BFCGs recruited as healthy volunteers) and from a Health Research Authority Research Ethics Committee (patients and BFCGs recruited through the NHS and independent hospices).

Analysis

Interview recordings were transcribed by a professional transcription service, checked, and anonymized. The qualitative software analysis program NVivo12© was used to facilitate analysis and management of the data (Bazeley & Jackson, 2013). A thematic analysis of the transcripts was undertaken through an iterative process including constant comparison (Braun & Clarke, 2019; Charmaz, 2006). Each transcript was independently coded within NVivo by at least two members of the research team and the development of the coding frames was discussed at regular team meetings. Separate coding frames were developed for each data set. This paper presents data from the themes relating to *preferences for place of death* from the Patient coding frame and *place of death* from the BFCG coding frame.

Results

Data were collected between October 2019 and February 2021. BFCG participants had the option of being interviewed by phone ($n = 12$) or video link ($n = 11$) and prior to the COVID-19 lockdown in March 2020, face to face ($n = 10$). One BFCG participant elected to conduct the interview through a series of emails. Six patient participants opted for interview by phone, five by video link and one by email.

Bereaved family caregiver (BFCG) interviews

BFCGs were asked to describe their experience of the dying and death of at least one significant other. No time limit was specified for these accounts, although the deaths most people described had occurred within the last few years. The 34 interviews included accounts of 47 deaths which are reported in this paper. Participants were also asked about how their experience of these deaths had influenced their anticipation of death and dying and their own preference for place of death. Several BFCG accounts were informed by participants' awareness of impending mortality due to their own age and serious ill health. Although most of the interviews were conducted after the COVID-19 lockdown, none of the accounts concerned deaths which had occurred during the pandemic.

The 34 BFCGs ranged in age from 19 to 82 years. The most common age group was 60 – 69 ($n = 14$). Only four participants were aged under 50 and 2 over 80 (Table 1). The majority were women ($n = 24$). The most common relationship with the deceased was mother ($n = 12$), with wives ($n = 7$), husbands ($n = 6$), fathers ($n = 5$), grandmothers ($n = 3$), and friends ($n = 8$) also constituting relationship groups. Cause of death was split between cancer ($n = 21$) and other diseases ($n = 24$) (Table 1).

Place of death

Fourteen of the 47 reported deaths occurred at home, 11 in hospital, eight in care or nursing homes, eight in hospice, one outdoors and three at Dignitas (Table 2). In the majority ($n = 30$) of cases, the deaths were reported as occurring in the deceased's preferred place. Most participants reported agreement between themselves and the dying person regarding the preferred and actual place of death. Only one of the 16 deaths occurring in hospice or residential care was reported to have occurred in the "wrong" place (a care home rather than own home). This compares with nine out of 14 home deaths and five out of 11 hospital deaths. In a few instances, such as following unscheduled hospital admission, place of death was considered the best available, rather than the ideal, option. This could be because the person lived alone and could not remain at home, or because the ideal location (hospice) was not available. Two relatives were reported to have died in hospital, despite a strong desire to remain at home. Only a few BFCGs described an experience which corresponded to the idyl of "the good death" at home: calm, peaceful, accompanied, in familiar surroundings and free from discomfort. For example, "So, he died upstairs on a sunny day with the windows open and birds singing, and it was lovely, actually. He just slipped away. And that doesn't happen to everybody" (Doris Taylor, wife of deceased).

Hospital was described in terms of active dissatisfaction in four cases. However, two BFCGs felt that it was wrong that their relatives had been discharged from hospital to a care home to die. Two others had not wanted their relative to be discharged home from hospice. This was considered unnecessarily disruptive at a critical point in the patient's last days. These participants felt their request for the patient to remain in hospital or hospice had been ignored because, they suspected, of a concern to free up beds for other patients and reduce the cost of care. Regardless of whether it was their preferred place, several participants described the death of their relatives at home as a difficult and distressing experience. Several deaths were unexpected and sudden, for example resulting from cardiac arrest (at home) or during surgery. These deaths were considered troubling and anomalous, and not subject to conventional judgements regarding the desirability or appropriateness of place.

Caring for the dying person at home

A few BFCGs described their strong commitment to caring for the dying person at home and were prepared to do whatever was needed to achieve this. Even for participants who could draw on professional expertise the difficulties involved in honoring this

Table 1. Bereaved caregiver characteristics.

	Pseudonym	Age	Sex	Deceased relationship to participant	Deceased diagnosis	Place of death
1	Jan Ferguson	57	F	Father	Dementia	Care home
2	Heather Smith	48	F	Mother	Ovarian cancer	Hospice
3	Carol Milligan	50	F	Mother	Renal failure	Home
4	Susan Crawford	62	F	Mother	Pneumonia	Hospital
5	Doris Taylor	82	F	Husband	Multiple co-morbidities	Home
6	Annie Draper	64	F	Mother	Liver cancer	Home
7	John Clark	65	M	Father-in-law	Cardiac arrest	Home
				Stranger	Accident	Outdoors
8	Naomi Jarvis	not known	F	Mother	Stroke	Hospital
9	Mike Burt	56	M	Wife	Cervical cancer	Hospice
				Mother	Unknown	Hospital
10	Felicity Burgess	65	F	Mother	Heart failure	Care home
				Husband	Multiple sclerosis	Hospital
11	Paula Stokes	63	F	Father	Colorectal cancer	Home
				Mother	Anorexia	Care home
				Friend	Pancreatic cancer	Home
12	Carrie Nolan	26	F	Grandmother	Kidney failure	Home
13	Lynn Fraser	19	F	Grandmother	Stroke	Hospital
14	Timothy Brentwood	46	M	Father	Metastatic mouth cancer	Home
15	Rob Haywood	79	M	Wife	Cancer	Hospice
16	Mark Hill	73	M	Friend	Mesothelioma	Dignitas
17	Jess Lewis	66	F	Friend 1	Bone cancer	Unknown
				Friend 2	Mesothelioma	Dignitas
				Friend 3	Progressive supranuclear palsy	Dignitas
				Grandmother	Pneumonia	Hospital
18	Annabel Grant	50	F	Father	Cancer	Hospice
19	Sheila Moore	81	F	Husband	Heart disease	Hospital
				Friend's child	Pneumonia	Unknown
				Friend	Multiple sclerosis	Hospital
20	Sarah Swain	68	F	Friend	Brain cancer	Nursing home
				Uncle	Frailty	Nursing/care home
21	Helen Bryant	56	F	Mother	Not stated	Home
22	Maureen Cooper	68	F	Mother	Dementia	Nursing home
23	Fiona Ross	59	F	Friend	Cancer	Hospice
24	Amy Watkins	67	F	Sister	Gynecological Cancer	Home
25	Maria O'Sullivan	69	F	Mother	Pneumonia	Care home
				Father	Sepsis	Care home
26	Bruce Irving	72	M	Wife	Bowel cancer	Hospital
27	Trevor Murray	79	M	Wife	Lung cancer	Home
28	Imelda Kelly	62	F	Husband	Prostate cancer	Hospital
29	Rachel Norris	63	F	Daughter-in-law	Bowel cancer	Hospice
30	Peter Quinell	75	M	Wife	Pancreatic cancer	Hospice
31	Hannah Porter	73	F	Husband	Head and neck cancer	Home
32	Les Vaughan		M	Wife	Cancer	Hospice
33	Diane Hamilton	67	F	Husband	Metastatic bowel cancer	Hospital
				Mother	Stroke	Home
34	Oscar Reed	66	M	Wife	Cancer	Home

commitment were considerable. Carol Milligan, who was a nurse and committed to caring for her mother at home, described how health professionals conveyed a view that her mother required a level of care that could only be provided in hospital or hospice and that it was unreasonable and unrealistic to expect that this could be achieved at home. Even with her expertise and knowledge of how to work the system, she described the last night "as a battle" when she and her mother were "left to it." She observed that it was not fair to leave families with decisions and responsibilities for care for dying patients who might be very distressed and agitated during their last hours.

> Because I'm a nurse, I became very involved in the overall management of her care. …. And she passed away at home, which is what she wanted. She did pass away at home. So that was, it was difficult, that last sorting out was a really difficult bit… I think all patients should get what they want when they die. But it shouldn't have to be at a cost or a battle, … but her last night was a battle. (Carol Milligan, daughter of deceased)

Notwithstanding their preferences and commitment, family capacity to manage care of the dying person at home depended on many factors, including the amount of pain and discomfort involved, the extent of family support available, and whether dying was protracted or quick. Carrie Nolan described her satisfaction that her extended family had been able to provide intensive care at home for her grandmother, but also expressed awareness that this had been possible because the death occurred quickly. Even her large and supportive family could not have maintained the required level of care for long. Although a minority overall, some deaths in all settings were described as difficult, distressing and with inadequately controlled pain. Oscar Reid was glad that his wife had died at home but felt that her pain and other symptoms had not been well controlled. He felt let down by hospice staff who had assured him that home care would be as effective as hospice care. Timothy Brentwood was glad his father had been discharged from hospital to die at home as he wished. However, he felt an adequate care package had not been put in place, and his father's pain was not well controlled. The family had to work hard to get the system to respond to their needs.

> …and it was the stress of watching him suffer, it was really hard. I don't get angry easily and I was getting really angry with the fact that people were just sauntering up four hours later and going, "Oh we'll give him twice as much." "Well, is that going to knock him out?" "Oh, yeah, but he won't be in pain."

Table 2. Patient participant characteristics.

	Pseudonym	Sex	Age	Diagnosis	Preferred place of death	Comments
1	Mr Jones	M	81	Cancer	Hospital	Would like to die in sleep
2	Mrs Rattray	F	82	Neurodegenerative disease	Home	Home if possible
3	Mrs Tomkins	F	58	Neurodegenerative disease	Hospice	Hope for sudden death
4	Mr Latimer	M	70	Cancer+	Home	Though expects to die in hospice
5	Mrs Cantwell	F	74	Cancer	Hospice	
6	Mr Gordon	M	74	Cancer	Home	Happy to die alone
7	Mrs Prentice	F	72	Cancer	Home	Home if possible, alternatively, hospice
8	Mrs Knight	F	68	Cancer	Hospice	
9	Mr Conran	M	81	Heart disease+	Home	
10	Mr Wells	M	71	Chronic obstructive pulmonary disease^{+}	Home	Home if possible
11	Mrs Wood	F	81	Cancer	Don't know, no preference	
12	Mrs Samuels	F	88	Cancer	Home	Home if possible

$^{+}$complex co-morbidity.

> "Yeah, but he don't want that." "Yeah, but it'll last longer and we won't have to turn up, won't have to keep coming back and forth." I was like, this is my dad you're talking about, not your schedule. And, again it's because they're probably rushed off their feet, people are too busy. (Timothy Brentwood, son of deceased)

Nearly a third of BFCGs explicitly referred to the desirability of the deceased dying in an institutional setting because of the difficulties of coping with care at home. This included four cases where the family had struggled with the demands of care at home and found the experience to be difficult and distressing. In other cases, a transition from home to hospital or care home had come as relief from a burden of care that was becoming intolerable, especially where the principal carer was herself an older person in poor health.

> Because my mum [said], "I can't cope with him at home," because just that week before he was admitted [to hospital] he had become incontinent on a couple of occasions. And she also said she was days away from saying to us, "I can't do this anymore. You know, I can't change your dad." So, we were just about to hit crisis point when this … event kind of took us out of crisis point, if you like. (Jan Ferguson, daughter of deceased)

Dying in institutional settings

Participants' experience of their relative's death in hospital was variable. Naomi Jarvis' mother had been admitted to hospital from her care home following a stroke. She was placed in a single room on a general ward, but Naomi did not consider this to be a nice place to die. During the week of her admission, she felt her mother received little time or attention from staff who seemed uncomfortable dealing with death and dying patients.

> So, the point I'm making is that in acute hospitals they might like to think that … they're giving people the best care when they're dying. But really from a humanity point of view there was so much that could have been done which would have been, could have been much better …. It was just not understanding anything and just being left to sit with her in a room and …. a lot of things could have been a whole lot nicer for myself and my sister just through human touches like, "Can I get you a cup of tea, you must be shattered? Can I see if I can find you one of these chairs that goes down into a bed." (Naomi Jarvis, daughter of deceased)

In contrast, Susan Crawford (daughter of deceased) was highly appreciative of the environment and quality of care her mother received in hospital during the last three weeks of her life, even though she experienced her dying to be difficult, distressing, and protracted.

> They were very kind at the [Hospital]. … She was in her own room even before the decision for end- of-life care was taken. So that was really quite comfortable and nice. And people were very kind because they put this little sign on don't they, the swan to say that it's end- of- life, an indication. And everybody from the cleaners to the nursing staff were really lovely.

Where families could not cope with the demands of care, especially where these were intense, death at home could be experienced as unpleasant and traumatic.

> And, as I say, based on the experience of dying in hospital that I've been close to and my mum, it seems to be that dying in hospital was more comfortable than what my mum had to go through. Probably better for the relatives as well, rather than having to go through all of that. So, I think if it was a place … like a hospice where if you was end-of-life you could go there and your relatives could go there, it would be a lot better. (Annie Draper, daughter of deceased)

The demands, and availability, of care at home were key issues in many cases. Hospice admission happened, for those who had access to it, when care at home became too difficult. However, Annie Draper felt that her mother had been influenced by a hospital ward nurse to express a preference to be discharged home to die. This was contrary to Annie's own expressed wish that her mother should remain in hospital. She felt that the responsibility of caring for her mother had a very negative impact on her own well-being and quality of life.

In relieving the considerable demands of care, admission to an institutional setting enabled relatives to focus on spending quality time with the dying person and helped to preserve positive memories of their last days. Jan Ferguson (daughter of deceased) described how a health care professional helped her overcome her resistance to her father's admission to a care home: "'Look,' she said, 'Have you considered that if you did put him in a home you could do the loving and the home could do the caring?'" Sarah Swain reflected on how her experience of her uncle's death had influenced her own preferences for place of death, which would be in residential care.

> So, what I had been thinking was that I would actually prefer to be in residential care. Because this uncle, … for the last few weeks of life, he was in a really lovely nursing home, and it seemed to me that that was the best care. … Because all your environmental needs disappear, and yet you've got

> this calm atmosphere where you can still have all of the lovely visits from people you love who come to say goodbye to you because it's your last few weeks. (Sarah Swain, niece of deceased)

The consequences for family members

The contemporary focus on the'good death places most emphasis on articulating and realizing the wishes of the dying person. The impact of these wishes on informal caregivers, and the difficulty of reconciling conflicting interests that may arise is largely ignored. These involve emotional as well as practical consequences, including concerns about contamination of place. Although it may be comforting for many, death at home may leave a residue of distressing and unwelcome memories. Although she felt very guilty about being unable to achieve her husband's very strong desire to die at home, Felicity Burgess (wife of deceased) reflected on the consequences this would have had for her.

> If my husband had died in our bedroom, I think I would have had to sell the house, because I don't think I could have coped with going to sleep in a room where he had died. So, actually, for me it was probably better that Frank did die in hospital in terms of coping with it afterwards.

Even when they appreciated their input, relatives could find the influx of staff and equipment involved in providing care at home to be intrusive and disruptive.

> And I think that's another thing that we forget, the invasion of your privacy, and your house is your safe place….and then when you've got all these different people coming in, and….in the last week of mum's life the hospice team were involved, and we had district nurses coming in. And it was, they all merged into one. … But I can honestly say now I don't know the name of anybody who came in in that last week, who they were, where they came from. (Helen Bryant, daughter of deceased)

Privacy could also be an issue during hospital admissions. As described above, side rooms could be valued for giving space and privacy but could also be experienced as an isolated and lonely place. In every location, the experience of care and quality of communication with staff was critical to participants' experience of their relative's death.

Patient interviews

Twelve interviews were completed with participants who knew they had a terminal diagnosis and limited life expectancy, recruited from four local hospices. Participants ranged in age from 58 to 88 years; seven were women and eight had a primary diagnosis of cancer (Table 2). Seven expressed a preference to die at home, though several qualified this by recognizing that this might not be possible, that hospice was an acceptable alternative, or that place was not important to them. Three participants said they would like to die in hospice, one in hospital and one had no preference.

> Yeah, well I've asked to go there [hospice] when I'm not very well, … when my health starts to go down and I can't walk, I've asked to go there. So, they've got it on their records, everybody knows that, so that's where I'm going. I don't want [my wife] to look after me, or my family. No, I don't want that. I know what it's like and I don't want that for her. No, I don't. (Mr Jones)

Mrs Knight lived alone and did not want to inconvenience her one close relative, who lived at some distance, with the burden or responsibility of caring for her at home. Mr Wells felt that hospice or even hospital was preferred to home because the quality of professional care would be superior to anything family members could provide.

Patient participants adopted a pragmatic approach to place of death, acknowledging that this would likely be determined by circumstances beyond their control. They were prepared to accept that they may not be able to die in their preferred place. Only two patient participants expressed a strong desire to die at home.

> Oh yes definitely. I don't want to go in a home. I don't want to stop in hospital. I want to die at home. There's no doubt whatsoever about that. We've put that in the care plan that where it's possible then I want to be at home. (Mr Conran)

Several of those who preferred to die at home acknowledged that this was an aspiration rather than a strong commitment – especially if they lived alone. However, the outcome was recognized to be strongly determined by how their illness progressed and the symptoms that arose prior to death. The aim was to remain at home for as long as possible, with hospice generally preferred as the fall- back option.

> Yes, I mean they know that if necessary then I'll go into the hospice. Obviously, I'd like to be home if I could, but depending on the symptoms and how it's going at the time will depend on where I end up sort of thing. But it's either going to be the hospice or home. (Mr Latimer)

Several participants preferred not to die at home because they rejected the prospect of family members having to provide personal care or experience the distress of witnessing their pain and deterioration. In addition to the desire to avoid burdening the people they loved with the responsibility for difficult and extended care, apprehension about being in pain, and the hope that they would not experience a "messy death" were the most strongly voiced patient concerns.

Discussion

Study participants gave diverse accounts of their experiences and preferences for place of death. Accounts of BFCGs and patients were congruent. Participants were pragmatic in accepting that, regardless of their preferences, location would likely be determined by factors beyond their control, including their care needs and available family input (Benson et al., 2018; Gerber et al., 2019; Hoare et al., 2015; Milligan et al., 2016; Thomas et al., 2004). Contrary to the rhetoric of current policy and professional practice, "choice" of place of death was not a strong priority and, in most cases would willingly be sacrificed in the interests of achieving comfort for the patient and reducing the burden of care for family members (Dying Matters, 2021; Gerber et al., 2019; Islam et al., 2021). Anticipated preferences were usually hypothetical and speculative. Preference for place of care was differentiated from place of death. Preferences were shaped by experiences of the past and founded on uncertainties about the future (Gerber et al., 2019). Good and bad experiences of death were described across all settings. Participants generally wished to remain at home for as long as they could, but opted to move, if possible, to hospice, if their symptoms intensified and their care needs became too great to be managed at home. Family caregivers also expressed concern about their capacity to cope with the challenges of caring for a dying person at home and varied in their willingness and ability to do so (Morris et al., 2015; Wahid et al., 2018). Rather than place of death, the most important priorities for patients and family care givers were that the dying person should be free from pain and discomfort and accompanied by the people of greatest significance to them (Hanratty et al., 2013; Islam et al., 2021; MacArtney et al., 2016; Marie Curie, 2022; McLoughlin, 2017; Waghorn et al., 2011; Wood & Salter, 2013). However, contrary to the promise of "the good death," and regardless of setting, dying was often described or anticipated by participants as likely to be difficult, distressing and "messy."

Even with an extensive package of professional support, family caregivers shoulder the bulk of day to day, hour to hour care of patients dying at home. Their input is essential to prevent unscheduled hospital admission and failure to cope with the demands of care is one of the main reasons why such admissions occur (Benson et al., 2018; Funk et al., 2010; Gerber et al., 2019; Hoare et al., 2019; Wahid et al., 2018). While professional effort is oriented to keeping patients at home, family members often struggle to cope with the relentless demands of care, especially if they are themselves old and in poor health and feel ill prepared and ill equipped to undertake complex tasks of personal care and medicines management (Broom & Kirby, 2013; Imison et al., 2017; Pollock et al., 2021; Wahid et al., 2018). Relatives who have internalized the imperative of providing care at home or feel under pressure to do so are likely to experience guilt and failure if the patient ends up being admitted to institutional care (Sathiananthan et al., 2021). We might ask: what is the relevance of choice for carers and what is their entitlement to limit the demands of care (Borgstrom, 2015; May et al., 2014)? Family members assume increasing responsibility for complex tasks which were formerly the preserve of professionals (Mair & May, 2014; Pollock et al., 2021). There is a continuing shift of cost and responsibility for care from the state to individual citizens (Broom et al., 2016; Exley & Allen, 2007; Imison et al., 2017). Patients and families should be supported to die at home where this is feasible and desired, but they should also be able to reject death at home and be confident that excellent end-of-life care will be available in all settings, including hospital and care homes (Gott et al., 2019; Robinson et al., 2016).

Patients' concern with minimizing the "burden" of end-of-life care on their family members has been widely reported (Broom & Cavenagh, 2011; Gerber et al., 2019; Hanratty et al., 2013; MacArtney et al., 2016; McLoughlin, 2017; Pollock & Wilson, 2015; Thomas et al., 2004; Wahid et al., 2018) but its significance as a salient expression of choice and as a criterion of a good death has not been sufficiently acknowledged: doing so would have substantial consequences for the organization and resourcing of end-of-life care. The nature of burden may be shifting and complex, encompassing emotional and relational, as well as physical, labor, and distress for both patients and family care givers (Broom et al., 2016; Broom & Cavenagh, 2011; MacArtney et al., 2016; Wahid et al., 2018). In addition, insufficient attention has been paid to how the experience and material alteration of the home impacts on dying patient and family members' sense of place and ontological security (Broom & Cavenagh, 2011; Exley & Allen, 2007; Milligan et al., 2016).

The professional focus tends to be on identifying and realizing patient choice to enable a good death. However, there is accumulating evidence that dying is experienced by patients and their significant others as a fundamentally relational experience. The good death for patients cannot be considered in isolation from the experience and concerns of family members and the patient's wish that their death should cause the least possible trauma, inconvenience and distress for others (Broom & Kirby, 2013; MacArtney et al., 2016; Sathiananthan et al., 2021). In addition to a strong desire simply to minimize the demands made on family members, patients' concern with reducing burden can be viewed as a form of reciprocation of care and a manifestation of agency in a situation over which they are reduced to having very little control. Although professionals strive to avoid unscheduled hospital admissions for dying patients, these may *become* an active choice. Patients may prefer institutional to home care to protect their relatives and the privacy and security of the domestic space (MacArtney et al., 2016; Thomas et al., 2004). They may wish to avoid the need for relatives to engage in personal care or the messiness and unpleasantness of dying, or to witness their suffering and physical and mental deterioration (Broom & Cavenagh, 2011; MacArtney et al., 2016). Several studies echo the views of our participants in expressing concerns about the transgression of boundaries which may result from intensive care of dying relatives and the desire to protect the legacies and relationships which would be jeopardized by the demands of care and witnessing the patient's decline and suffering (Benson et al., 2018; Broom & Cavenagh, 2011; Exley & Allen, 2007; Funk et al., 2010; Gerber et al., 2019; Islam et al., 2021; Wahid et al., 2018). The protection of memory extends also to a wish to avoid the contamination of place which may be felt by remaining occupants following a death at home (Islam et al., 2021; Seymour et al., 2007). That patients are concerned to "die well" for their relatives as well as themselves, is a critical insight which has been largely excluded from the dominant discourse about patient choice and "what matters to me" (Broom & Kirby, 2013; The Choice in End of Life Care Programme Board, 2015). Dying involves a pragmatic co-construction of care, primarily between patients and their family members with health care professionals in a supporting role.

The legacy of COVID

The desirability of dying at home has been further called in question by the experience of the COVID-19 pandemic (Richards & Rowley, 2021). Deaths in usual place of residence increased from 47% in 2019 to 52% in 2020 (Nuffield Trust, 2021) but this was not considered to be a welcome development. The majority of these additional deaths were not related to COVID but are thought to result from patients' fear of contracting COVID in the event that they were admitted to hospital, or reluctance to burden an over- stretched health care system (Richards & Rowley, 2021). Home deaths during the pandemic are seen as often undesirable, under duress and without adequate professional or family support. It remains to be seen how the experience of dying at home during the pandemic shifts attitudes to preferred place of death and how this experience has highlighted the wider inequities of dying at home, without adequate social or professional support, in precarious conditions of insecure or inadequate housing conditions, or in situations of material and economic deprivation (Richards & Rowley, 2021).

The COVID-19 pandemic has called in question whether dying at home could and should be considered an indication of a good death. However, home cannot be an ideal place for the many people who lack the social and economic resources required to enable adequate support (Pollock, 2015; Rowley et al., 2021). Current policy regarding choice and place of death is out of sync with the real-world experience and options of many people and with the preferences and priorities of patients and the public. The reality of death in any setting, including home, is often far from the idealized representation of the good death. As indicated by the study findings, there is considerable diversity in experience and preferences for death and dying, but place is rarely a priority.

In reality, as opposed to the romantic idealization of the good death discourse, a wide range of socioeconomic factors determines place of death, regardless of choice. (Milligan, 2016; Neergaard et al., 2019; Rowley et al., 2021). The uncertain and contingent nature of the factors determining where and how death occurred was widely appreciated among study participants. The organization and resourcing of end-of-life care must come to terms with the reality of a continually aging population in which neurodegenerative disease and frailty account for increasing numbers of deaths (Pollock & Seymour, 2018; Teggi, 2020). The very old and those with dementia are least likely to die at home, pointing to both the difficulties of providing adequate home care for patients in these circumstances and the need to greatly increase the capacity of the care home sector as leading providers of end-of-life care (Teggi, 2020).

In exaggerating the importance of place rather than acknowledging the public prioritization of comfort, current policy overlooks the difficulties which patients and family carers may experience in providing care at home (Broom et al., 2016; Coe, 2020;; Exley & Allen, 2007; Morris et al., 2015) and the limited amount of cost saving which may be achieved (Imison et al., 2017) particularly if the very considerable financial as well as personal costs for carers are considered (Gardiner et al., 2020; Robinson et al., 2016). Internalization of the cultural script about 'the good death' at home reinforces expectations about family responsibilities to provide care, which they may struggle or be unable to provide, and the guilt that results from a sense of failure to discharge key obligations (Broom et al., 2016; Exley & Allen, 2007). The promotion of the illusory ideal of 'choice' regarding place of death has been underpinned by an ethnocentric, middle class, professional ideology on the one hand (Lofland, 2019; Richards, 2022; Sathiananthan et al., 2021) and a concern to reduce the escalating costs of end- of- life care, on the other (Imison et al., 2017; Pollock & Seymour, 2018). The result has been a relentless demonization of the hospital as an inadequate and inappropriate place of death (Coe, 2020; Robinson et al., 2016). The key role of care homes as providers of end-of- life care has been overlooked (Teggi, 2020), as have the clear but largely unattainable preferences of many people to die in hospice (Hoare et al., 2015; Thomas et al., 2004). The current and projected increase in deaths in care homes, along with the strength of patient preference for death in hospice suggests a need for reassessment of current policy for promoting death at home (Teggi, 2020; Thomas et al., 2004). Good care must be available in institutional settings which enable patients and families to protect and enjoy the social relationships which are of greatest significance to them.

Limitations and conclusion

A strength of the study was to engage the accounts of the lived experiences of bereaved family caregivers and terminally ill patients, the latter especially being a hard-to-reach group, whose views have rarely been presented. It included a reasonable balance of men and women, but a concentration of older, White British, and middle-class participants. Given the recruitment of patients and some BFCGs from hospices, it could be expected that these individuals may have a positive opinion of such institutions as a place of care and death, and their views may not be typical of the wider population.

The study findings support a growing body of qualitative evidence which point to public pragmatism and flexibility in relation to place of death, and the misalignment of current policy with public priorities which are for comfort and companionship at the end-of-life, regardless of place. Policy has been formulated with little consultation or input from the wider public and apparently without due consideration of the changing needs of an aging population. While framed within a rhetoric of choice and beneficence, the discourse of the good death has largely written out the distress and difficulty which is intrinsic to the experience of dying. Findings reported from this study indicate the considerable challenge and distress for family caregivers as well as patients involved in providing care at home. The discourse of 'the good death' at home risks raising expectations which may not be met and imposing excessive obligation on family members who often struggle to provide the necessary level of care. The option to die at home may only be feasible below a threshold of need, above which institutional care of some kind is required. This threshold may become increasingly hard to meet as demographic changes result in more people living alone and a continuing increase in the numbers of people dying in great old age, especially with frailty and dementia.

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