Dying in the margins: Experiences of dying at home for people living with financial hardship and deprivation

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A B S T R A C T

Home dying is a policy indicator of 'quality dying' in many high-income countries, but there is evidence that people living in areas of higher deprivation have a reduced likelihood of dying at home. However, there is limited research which centres the views and experiences of people living with both socioeconomic deprivation and serious advanced illness. We deployed visual methods to address this gap in knowledge, focusing on barriers to, and experiences of, home dying for people experiencing poverty and deprivation in the UK. We used photovoice and professional documentary photography between April 2021 and March 2023 with eight participants with serious advanced illness, six of whom had died by the end of the study. We also worked with four bereaved family members to create digital stories. This produced a large volume of multi-modal data which we analysed using a thematic, iterative, interpretive approach. Key findings included the high costs of dying at home, the nature and impact of which were conveyed by images such as a heating thermostat set to low. Images also expressed how for some participants, the environment inside and outside the home was experienced as oppressive and alienating because of cramped, materially poor social housing, as well as urban noise, crime, mould and damp, and a lack of access to outside space. Nevertheless, the home environment was important to all participants, particularly as a site to support the continuation of their identity and autonomy, and some were explicit about wanting to remain at home for as long as possible. This study provides unique insights regarding the significant policy shift needed to improve the extent and experience of home dying for the growing number of people dying in the context of financial hardship and deprivation both in the UK, and elsewhere.

1. Introduction

Place of death is a government proxy indicator of 'quality dying' in most Western countries, including in the UK (Public Health England, 2023; Scottish Government, 2018). Increasing the proportion of deaths at home and reducing time spent in hospital at the end-of-life has become an international policy priority (Robinson et al., 2016). After many decades where dying and death were highly medicalised and sequestered within institutions (Illich, 1976), this policy shift indicates a significant social change. The shift can be attributed to factors such as the considerable cost of potentially avoidable hospital admissions to publicly funded healthcare systems, as well as the risk of over-treatment (National Confidential Enquiry into Patient Outcome and Death, 2008), poor quality care (Parliamentary and Health Service Ombudsman, 2015), and hospital acquired infection (Guest et al., 2020). There is also extensive and consistent evidence that home is the preferred place of death for most people, regardless of their socio-economic status (Gomes et al., 2013).

1.1. Place of care

Current evidence suggests that there is a 'social gradient' at work in relation to dying at home. People living in more socio-economically deprived areas in global North countries, including the UK where the data for this article were collected, have been shown to be less likely to die at home and more likely to experience (often unscheduled) hospital admissions and intensive treatment in the last few months of their life (Davies et al., 2019). During the Covid-19 pandemic, while deaths at

home increased across all deprivation groups, people living in the most deprived areas experienced a smaller increase than people living in the least deprived areas (Sleeman et al., 2022).

Many commentators have rationalised that place of death represents a crude and unreliable indicator of *actual* experience or quality of care. Survey data about preferred place of care and death is critically flawed, researchers argue (Pollock, 2015) and preferences vary with age, gender, ethnicity, and cultural identity, not to mention previous experience, stage of disease, and with concerns about being a burden to other family members in the home (Cox et al., 2013). For people living in more socio-economically deprived areas, there is some evidence that they may derive more benefit from being in hospital at the end of their life above and beyond symptom management, because they "feel safe" in hospital (Robinson et al., 2018) and because it can provide "a rare source of demonstrable support" in the form of people to talk to (Kangovi et al., 2013, p.1201)

Home is both a physical, material place *and* a 'social imaginary' – a set of ideas and feelings (Blunt & Dowling, 2006). There is no doubt that home is romanticised in international end-of-life care policies because it embodies various idealised qualities and values such as privacy, warmth, comfort, autonomy and security (Blunt & Dowling, 2006) all derived from long-established Euro-American ideology of individualism with its links to, and promotion of, property ownership (Locke, 1980). Some have argued that these are middle class, ethnocentric values which should be challenged (Pollock et al., 2023), and that there is a problematic equivalence between 'house', 'home' and 'family' which doesn't account for the fact that some people's houses might not always be that homely and that people may live alone (Gott et al., 2014). People experiencing poverty and deprivation can live in inadequate housing which may be damp or cramped and poorly heated because bills are unaffordable. They may also not be able to control who comes into the property. In sum, although place of care and of death has been extensively critiqued as an indicator of 'quality dying', we consider it analytically useful as an entry point into examining the complexities and socio-economic disparities in end-of-life experience more broadly.

1.2. Socio-economic inequities

In recent years, there has been an 'equity turn' in palliative and end-of-life care (Richards, 2022). This has led to an increased focus on developing equity-informed palliative care and shining a light on the invisible privileges inherent within existing systems of care (Stajduhar & Gott, 2023). However, demographic changes may threaten this nascent equity focus. More people will be dying in the decades to come (a 25% increase in the UK by 2048 (Marie Curie, 2023)) and they will experience higher levels of multi-morbidity, indicating a greater need for palliative care. This is likely to put additional strain on hospitals and existing community services and potentially leave less scope for rebalancing the distribution of resources to those with greater end-of-life care needs, specifically those experiencing poverty and deprivation.

Enabling more home dying, then, is not just a matter of meeting quality benchmarks. It is becoming a matter of necessity given the anticipated upward trend in the number of people dying in the UK, and the limited capacity of hospitals and hospices to provide beds for those people. As Kellehear points out, "though many people become dead in total institutions, the longer part of living-while-dying is outside of custodial care" (Kellehear, 2017, p. 11). There is an urgent need, therefore, to consider people's day-to-day experiences of dying at home over several months when they are struggling with financial insecurity. What role do different housing types and state-funded care packages play in enabling people to remain at home? What measures are likely to enhance people's dying experiences and the experiences of those closest to them? These were the questions which shaped our study, the aim of which was to examine barriers to, and experiences of, home dying for people experiencing poverty and deprivation in the UK.

2. Materials and methods

2.1. Rationale

In palliative and end-of-life research into socio-economic disparities, there has been an overwhelming focus on measurement, rather than on people's actual lived experience (Richards, 2022). Professionals or family carers are often included in research as proxies due to the perceived challenges of recruiting people who are themselves at end-of-life (Kars et al., 2016). This presents a problem because, as Kellehear points out, while there might be an "overlapping reality" between carers/onlookers experiences and those who are dying, they are different in crucial ways (Kellehear, 2022).

In order to hear from and enhance the involvement of those traditionally placed 'at the margins' in this research field, we adopted a qualitative participatory approach informed by a feminist ethics of care and also influenced by Indigenous ethics which centre self-determination and relational, non-extractive research practices (Gott et al., 2017). The study draws from a social constructivist, interpretivist tradition and our chosen methodology was qualitative, longitudinal, participatory and in-depth.

We deployed three distinct visual methods - photovoice, digital storytelling and professional photography. Visual methods are very rarely used in palliative and end-of-life research (Richards, Quinn, Mitchell, Carduff, & Gott, 2023). The rationale for using visual methods in our study was to: enhance participant's involvement, confidence and control over the research process as photovoice and digital storytelling are specifically designed to do; enable creative expression, meaning-making and legacy building through photography and digital storytelling; and to generate imagery which could be used to tell stories of dying which are less visible within palliative and end-of-life care policy and research, but arguably, also within the public imagination.

In this article, we report on findings from Phases 1 and 2 of the study. Phase 1 involved people who were themselves nearing the end of their lives in conditions of financial hardship and deprivation, and their bereaved carers. In Phase 2, we worked solely with bereaved carers of people who had died in conditions of financial hardship and deprivation in order to create digital stories about a specific aspect of that experience.

Ethical approval for Phase 1 was granted by the North of Scotland NHS Research Ethics Committee and NHS Greater Glasgow & Clyde granted R&D approval. We obtained approval from the Research Governance Committee at each hospice site. Ethical approval for Phase 2 was granted by University of Glasgow's College of Social Sciences Research Ethics Committee.

2.2. Data collection

Data for Phases 1 and 2 were collected between April 2021 and March 2023. All the different sources of data collected during these two Phases are listed in Column 9 of Table 1.

2.2.1. PHASE 1 (photovoice and professional photography with people nearing the end-of-life)

In Phase 1, we recruited people who: (1) were considered by relevant health care providers to be living with serious advanced illness and nearing the end-of-life and (2) living in areas of relatively high deprivation and self-reported as experiencing financial hardship. Potential participants were initially approached by intermediaries (doctors, nurses, social workers, physiotherapists, and community link workers) working in two hospices and in GP practices which agreed to be involved in the study. If individuals expressed interest in taking part, they were referred to the project researcher who initiated the consent process. The source of referral and demographic details of our Phase 1 participants are detailed in Table 1.

Photovoice is a participatory research method pioneered in the early

Table 1
Details of Phase 1 Participants, including where recruited and materials collected.

Name	Age	Gender	Diagnosis	Referred by	Family situation	Tenancy type	SIMD 2020 rank (1 = Most deprived, 10 = Least deprived)	Data sources	Location at end-of-life
Andy	53	Male	Throat cancer	Hospice	Single	Social rented	1	Photovoice (10); 3 sessions with professional photographer	Hospice (Admitted 1 month before death)
Max	65	Male	Anal cancer	Hospice	Single	Social rented	2	Photovoice (20); 4 sessions with professional photographer; post-death interview with friend/carer	Hospice (Admitted 1 week before death)
Marie	46	Female	Appendix cancer	Hospice	Single parent	Private rented	3	Photovoice (35); 3 sessions with professional photographer; 1 touchpoint; post-death interview with Aunt	Hospice (Admitted 1 month before death)
Donna	56	Female	COPD, Liver cancer	Community Link worker (primary care)	Single parent	Social rented	1	Photovoice (10); 2 sessions with professional photographer; 1 touchpoint	Alive
Amandeep	22	Male	Duchenne muscular dystrophy	Hospice	Lives with mother and siblings	Social rented	3	Photovoice (10); 2 sessions with professional photographer; 6 virtual touchpoints	Alive
Stacey	39	Female	Secondary breast cancer (metastasised to Brain)	Community Link worker (primary care)	Lived with husband	Social rented	2	Photovoice (80); 4 sessions with professional photographer; 2 touchpoints; post-death interview with husband	Hospice (Admitted 3 weeks before death)
Liz	73	Female	Liver cancer	Hospice	Had partner, lived separately	Social rented	1	Photovoice (150); 3 sessions with professional photographer; 8 touchpoints	Hospice (Admitted 4 weeks before death)
Margaret	64	Female	Lung cancer	Hospice	Single parent	Owned home	1	3 sessions with professional photographer; 2 touchpoints; post-death interview with daughter	Hospice (Admitted 4 weeks before death)

1990s by Wang and Burris (1997) and is designed to: (1) empower participants through the taking of their own photographs; (2) promote critical dialogue and knowledge through discussion of their photographs; and (3) reach policy-makers. There is an established body of literature supporting its use with structurally marginalised groups (Loignon et al., 2020). Recruited participants were given a digital camera (some used their phone cameras) and invited to take an unspecified number of images "of the things and experiences that are important to you, the things you are finding helpful, as well as those you may be worrying about." When COVID-19 restrictions allowed, the project researcher arranged face-to-face touchpoints to view and discuss the images. The number of touchpoints for each participant are listed in Table 1 and we worked flexibly with each participant depending on their desire to meet and whether they had managed to take any images.

The touchpoints were recorded and transcribed verbatim and formed part of the research team's understanding of what the images showed and how participant's felt about what they showed. The researcher stayed in regular contact with most participants via phone and email between touchpoints. Length of involvement in the study ranged from 2 months to 2 years. Six of the 8 participants were involved until they died, one participant was alive and saw her involvement as a discrete time-bound engagement, and one participant was alive and involved up until the end of the study. Where possible, we also conducted a follow-up interview with each participant's main carer or closest relative in the months following their death.

For Phase 1, all participants were invited to work with professional documentary and portrait photographer Margaret Mitchell who was commissioned to convey aspects of participants' experiences which they were not able to capture themselves through photovoice. During the various lockdowns, Margaret Mitchell's press pass enabled her to meet with participants in the hospice when researchers were not permitted to do so. She was also able to support some participants with the technicalities of operating the project camera. All participants agreed to work with Margaret Mitchell and Table 1 details the number of visits she conducted. We have reported in detail on these two methods elsewhere (Richards, Quinn, Mitchell, Carduff, & Gott, 2023) and so limit the discussion here for reasons of space.

2.2.2. PHASE 2 (digital storytelling with bereaved carers)

Digital storytelling is a form of co-production offering people the opportunity to create multi-media narratives about important life events (Lambert et al., 2003). The resultant 2–3 min digital stories involve layering of photographs, video footage, and music over a narrated script and are considered reusable learning objects. We aimed to recruit people: (1) who were between 2 months and 2 years bereaved and; (2) whose friend or relative had experienced financial hardship at the end of their life. Our intention was to capture the reflections of bereaved carers whose friend or relative wanted to die at home and what more could have been done to help them. Recruitment involved cascading advertisements nationally through bereavement support charities, foodbanks, hospice chaplaincy services, on social media and elsewhere.

Due to the COVID-19 mitigation measures that were in place through much of our study, we adapted the digital storytelling method, supporting relatives to create their stories online. In addition, significant recruitment challenges prevented us utilising the usual group workshop format and instead we worked individually with participants. Participants met the researcher virtually and discussed their relative's experiences in a recorded interview, as well as identifying the possible visual media they would like to use. All participants requested the researcher lead the script development. The transcribed interview was used as a starting point for the script and edited by the research team to around 350 words, which was then edited and approved by the participant. The participant and researcher then met online to record the audio. The various digital assets were then passed on to a professional video editor rather than being edited by participants themselves. This was because, under pandemic conditions grieving participants lacked the time or

inclination to technically edit the stories themselves.

2.3. Data analysis

Inspired by Tishelman et al.'s (2016) use of "research retreats", authors Richards, Quinn and Carduff met for 4 full days over an 8-month period to engage in a joint, in-person, iterative, thematic analysis exercise. We collectively familiarised ourselves with the images, textual data, and audio data for each participant and identified individual and cross-cutting themes (Spencer et al., 2014). During these sessions, analysis of the visual data followed the questions outlined in Box 1 (below) and an initial coding tree was developed. Notes were taken by Richards during the sessions, which were also recorded for later cross-checking.

All data (both visual and textual) were imported into the software programme NVivo and coded together by Richards. The coding tree was then further developed. Discussion of the themes continued in full team meetings with all authors over several months as coding was ongoing. Codes which related specifically to participants' home environment or place of care were collated and form the basis of this paper. Images and quotes have been selected which best represent or support the themes identified.

3. Participants

We recruited 8 participants to Phase 1 and 4 participants to Phase 2. Table 1 provides relevant data about the participants recruited for both phases. Six of the 8 participants from Phase 1 had died by the end of the study. All participants requested to have their real names used alongside their images.

4. Findings

4.1. Costs at home

There are considerable costs associated with dying at home, primarily electricity, heating, equipment, taxis, and care costs. Some participants were housebound and therefore had the cost of staying warm in their homes throughout the day. Fig. 1 shows a photovoice image taken by Liz of her thermostat, which had been turned down to keep the heating bills low.

Some participants used electric heaters to localise heat in one room or to top up inefficient heating systems:

> The heaters cost so much to run, but during my treatment I'm so cold that my central heating just isn't enough. (Marie)

The cost of the electricity required to run essential equipment was also high. Amandeep, for example, required non-invasive ventilation throughout the night, an electric hoist to get in and out of bed, and electricity to charge his mobility scooter. Fig. 2 shows Amandeep in his room at home and his assisted photovoice images give a sense of the

Fig. 1. Photovoice image taken by Liz of her thermostat ©Dying in the Margins 2022 all rights reserved

array of equipment around him.

> All my stuff runs on electricity, and the electricity prices, they've skyrocketed. (Amandeep).

In Fig. 2, you can also see the family washing machine and dryer to the left of Amandeep's bed. The volume of washing which can accompany living with a terminal illness (due to soiling, vomiting, and general bodily fluids) also pushes up electricity bills. One of our participants washed her clothes in the bath rather than use her washing machine in order to keep her bills down:

> I've got low living costs […] I don't put the heating on. I try and cut down and wash things in the bath. (Liz)

The cost of taxis to and from medical appointments, as well as to and from the hospice, was also mentioned by participants as a significant cost they had to bear:

> I can't get to a hospital without a taxi. So there's taxis to the Beatson (hospital), taxis to Stobhill (hospital), another one I had to go to was at the Jubilee (hospital), nearly £30 there and back. If you've not got money coming in, it's a bloody big sum of money! (Margaret)

The alternative to taxis was buses, and participants spoke of having to take multiple buses to get to hospitals and the difficulties and discomfort of walking to bus stops, waiting, and then sitting for a long time whilst in pain. One bereaved relative from Phase 2 reported that his brother, Steven, who was experiencing deep financial hardship due to being considered ineligible for state disability benefits, could not afford a taxi to his hospital appointment and so had no choice but to sit on public transport for 90 min, and to endure a further 20 min walk at the end of that journey. This was all whilst, according to his brother, he was experiencing "breathlessness, infirmity and pain", and indeed he died in a hospice a week later.

The final significant cost identified by participants was the cost of paying for care when state-funded care was deemed insufficient. Jo, a bereaved relative, reported that her husband Barry, who had significant care needs because of a brain tumour, was offered what in her eyes was an insufficient care package. At different points, Jo was advised that paying for private carers was the only way to enable Barry to die at home, but this would have pushed the family into considerable debt. As an NHS physiotherapist, Jo was able to research her situation and draw on her professional contacts, finally securing a state-funded live-in carer which enabled him to die at home. Jo and Barry's case illustrates the immense difficulties securing care packages, even for people with

Fig. 2. Assisted photovoice image taken by Amandeep of his bedroom and equipment requiring electricity ©Dying in the Margins 2022 all rights reserved

significant health literacy and social capital to leverage.

Other participants who lived alone with no family or friends able to care or advocate for them were entirely reliant on what was offered by the state. Participants knew that without people to care for them at home, it was likely they would spend their final days in an institution:

> What if I lived in Milngavie and was surrounded by loving sons and daughters that have done really well and had a beautiful house, blah, blah, was a professional person. I suspect my care would be different. (Liz)

As other studies have shown, it is unlikely someone can die at home if they do not have family or friend carers who can support this (Cai et al., 2021).

The high costs of dying at home are difficult for individuals and families to meet when income from paid work ceases. The participants in our study used personal savings and government social security to pay these costs, but sometimes these were insufficient and they either went without (heating/food/taxis) or had to borrow money and get into debt. Moreover, as Steven's experience shows, people are not always able to access their social security entitlements, causing them significant hardship and distress in the last months and weeks of life.

4.2. Home and environment

For some participants, the environment inside and/or outside the home was experienced as oppressive and alienating.

4.2.1. Inside environment

Some participants struggled with cramped conditions which they felt affected their quality of life. Stacey, for example, expressed desperation at her housing situation and the fact that there was not enough space in her one-bed flat to accommodate her, her husband, and her mother, who was helping to care for her while her husband worked. Stacey's mum slept on the sofabed in the living room (see Figs. 3 and 4).

> *Mum*: The bed sitting here constantly […]
>
> *Husband*: It's the living room
>
> *Mum*: I mean, where can we escape to?

Stacey was "phoning and phoning constantly" over a 6-month period to be prioritised for a larger, ground floor flat by her housing provider. There were also insecurities *within* the home environment, with walls

that were seemingly porous to outside elements, such as water, damp, mould, and noise. Living in the inner city, surrounded by a significant road network, Stacey complained of noise pollution:

> I'm in this overcrowded house and there are roadworks outside blasting away and I've two brain tumours. (Stacey)

Similarly, Liz took photovoice images of the roadworks outside her

Fig. 3. Photovoice image taken by Stacey of the sofabed her mum slept on ©Dying in the Margins 2022 all rights reserved

Fig. 4. Professional portrait of Stacey and her mum on the sofabed in the living room ©Margaret Mitchell 2023 all rights reserved

flat (Fig. 5), noise from which caused her distress, as can be seen in the handwritten notes she photographed.

Liz also took photos of the mould inside and outside of her bedroom (Fig. 6). Liz was dying of metastatic lung cancer and the mould and damp in her flat likely exacerbated her breathing difficulties.

When she raised the issue of the mould with her housing association, she felt that she was disbelieved, or worse, that she was being blamed:

My bedroom has got worse. The housing worker came out and said it was my fault. It's not, it's outside. I now know it's outside. It's black outside. (Liz)

The issues with space, noise and damp which our participants experienced *inside* their flats and houses at the end of their lives caused them distress. This distress was exacerbated by their interactions with social housing officials, either because they felt there was no sense of urgency or even that they were being blamed for the situation. Several participants reported that the social housing system appeared unresponsive to individuals' urgent needs. Participants also reported that representatives of those organisations also sometimes failed to show compassion in their interactions or to recognise the distress which unresponsive systems were causing them.

4.2.2. Outside environment

Some of our participants spoke about wanting access to outside space in their last few months of life. Fig. 7 is a photovoice image taken of Marie enjoying the sunshine with friends in the communal area outside her flat.

You see about the stairs, right, the stairs are a big, big problem. [Max]

However, for participants in high-rise flats, sometimes there were barriers to accessing outside space due to multiple flights of stairs and either no lift, or the lift not working. This left them trapped in their flats.

Even participants who lived on the ground floor could still have stairs to navigate when trying to access outside space. Amandeep commented:

I can't even get to my back garden because there are stairs. In the summer weather, I can't even take advantage of the good weather, because I can't get out the back. (Amandeep)

Living in high-rise flats also presented an issue in terms of access for health and social care professionals. Nicola, a bereaved relative from Phase 2, spoke about the difficulties providing care to her mum who lived on the 14th floor of her block of flats when the lift stopped at the 13th floor. In Nicola's view, this was a major barrier to her mum being able to die at home, as it impeded access for carers, as well preventing the installation of necessary equipment. While stairs can feature in homes across the social gradient, there are more flats and particularly more high-rise flats in more deprived areas (Kearns et al., 2012). Stairlifts are means-tested and as their installation is at the discretion of local authorities, there is evidence to suggest that people with terminal illnesses are *deprioritised* for such home adaptations because the benefit derived would be short-lived (MND Scotland, 2022).

For participants who *did* manage to access outside space, some were faced with urban spaces which were neglected, run down, or left them feeling insecure or threatened. Margaret, for example, struggled to use her Motability scooter to get to her local shops because the pavement was "sort of smashed to smithereens." Other participants did not really have anywhere to go because the urban environment offered little in the way of green spaces or even places to sit.

The lack of anywhere to go in an environment which was difficult to move about in, or find a place in, left participants feeling trapped. Stacey commented:

I'm stuck in here with nowhere to sit outside as I can't walk to the park anymore (…) I just want out of here. I just feel trapped up here. (Stacey)

High crime rates also affected some participants' views of their neighbourhood (see Fig. 8). Andy, for example, had no option to return home to his flat as it had been broken into during a hospice admission. Margaret Mitchell took a photograph of his boarded up flat for her project diary (Fig. 9).

Other participants took their own photovoice images of their neighbourhood to convey the insecurity they felt, particularly at night-time.

Commenting on her photovoice images (Fig. 10), Liz reflected:

I don't feel safe. If I go out, my partner has to take me home in the evening and you see criminal activity going on in my block, which is difficult. I don't want this to impact on my care. (Liz)

Some participants resigned themselves to staying indoors because they felt that the outside environment was inhospitable to them in their final months of life. Other participants sought sanctuary outside of their homes and their estates. Liz spent her days in the public library seeking both warmth and security (see Fig. 11).

I'm always here, I see this as my safe place. (Liz)

For others, the hospice became a sanctuary, either because their homes had become just too insecure, like Andy's, or because they sought the respite of a calmer space where they were the focus of attention. For example, Amandeep was cared for at home by his mum, a single parent, and his bedroom was overcrowded with medical equipment, washing machine etc. (see Fig. 2). The image taken by Margaret Mitchell of Amandeep in the hospice, which he visited frequently for symptom control and respite, shows a markedly contrasting environment (see Fig. 12).

Amandeep's view of the hospice was that "it's like a hotel […] I get treated like a king." For this reason, he said when the time came, he would like to die in the hospice.

A final important point to note about participants' outside environments was that some participants located the genesis of their illness in their environment. Experiences of poverty can render people
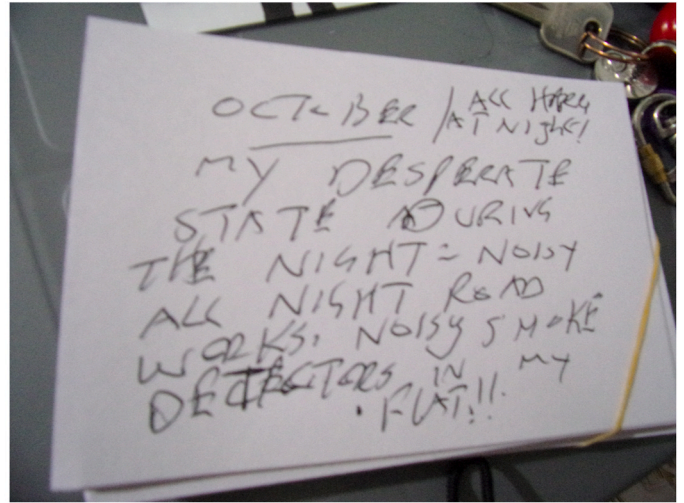
Fig. 5. Photovoice images taken by Liz of roadworks outside her flat and a note about the distress caused by the urban noise ©Dying in the Margins 2022 all rights reserved

Fig. 6. Photovoice images taken by Liz of mould inside and outside her flat ©Dying in the Margins 2022 all rights reserved

Fig. 7. Photovoice image take of Marie outdoors on communal 'green' ©Dying in the Margins 2021 all rights reserved (For interpretation of the references to colour in this figure legend, the reader is referred to the Web version of this article.)

Fig. 8. Project diary photograph of Donna struggling on the stairs ©Margaret Mitchell 2022 all rights reserved

particularly vulnerable to environmental and occupational exposure to known carcinogens (Marmot et al., 2010). Margaret, for example, believed her cancer was caused by pollution, growing up in an industrial city, living on a busy road, and working above a bus station for years:

> We went to school in the peasouper. You were all holding onto each other, it was so thick. You couldn't see anything. (Margaret)

There were also reports from participants of feeling judged and dismissed by healthcare professionals when reporting illness. Liz reported that her doctor attributed her physiological symptoms to social causes:

> In the hospital a year ago, I was told I had social problems and mental health problems, despite the fact I had very clear reasons [for being there]. I'm wondering if every woman, particularly with a chronic condition, in a very bad area, is labelled with this […] even though I've been admitted with clear, clear medical symptoms, I'm offered anti-depressants. (Liz)

While the doctor's response, as described by Liz above, appears to evidence recognition of the social determinants of mental health, albeit a medicalised response in the form of anti-depressants, the even more striking aspect of Liz's account is that her doctor appeared to neglect the causal link between poverty and serious physical diseases such as cancer.

In sum, the environments both *inside* and *outside* our participants' homes were in some cases detrimental to health and a cause of insecurity and distress. The importance of public spaces and physical hospices which could provide safety and sanctuary, was identified as a key theme in the visual and textual data.

4.3. Home and identity

We identified that for some participants, despite the material deprivation and insecurity experienced, their home environment nevertheless supported the continuation of their identity into the last phase of their life. Visual and textual data showed that our participants' individual and relational identities were manifest in, and expressed through, their homes and that this was a key driver to remaining at home, despite the additional costs and insalubrious environment.

Through various creative home-making activities, even whilst very sick, some participants were able to reflect a sense of their personal identity, biography, and relatedness to both people and place. For Marie, the last year of her life was spent mostly in her flat. She spent small amounts of money which she could not afford on making her home a sanctuary. Fig. 13 shows the "treats" she indulged in to provide comfort for herself after bouts of chemotherapy and a focus for companionship with her daughter.

> I love my bed […] The dark nights enable me to have an excuse to go to bed early and light candles. I either read or watch TV in comfort and warmth and it's really relaxing. (Marie)

Through pampering sessions with her daughter, Marie used her limited financial resources and energies to actively construct the spatial imaginary of her home to support affective legacy-building with her daughter.

Liz's creative flare was evident in her one-bed housing association flat. Clothing featured in abundance in her photovoice imagery (Fig. 14) and she spent her time at home putting together idiosyncratic clothing ensembles which she felt gave expression to her unique identity and which she would wear out in her walks around the city, visiting charity shops and churches.

Liz told the project researcher that she knew her flat would be considered "cluttered" by health and social care professionals. Indeed, the research evidence suggests that hoarding is more prevalent amongst people who have experienced trauma in their lives and people experiencing financial hardship are more likely to have experienced trauma (Landau et al., 2011). For Liz, these belongings were integral to her

Fig. 9. A participant's boarded up flat - Project Diary ©Margaret Mitchell 2021 all rights reserved
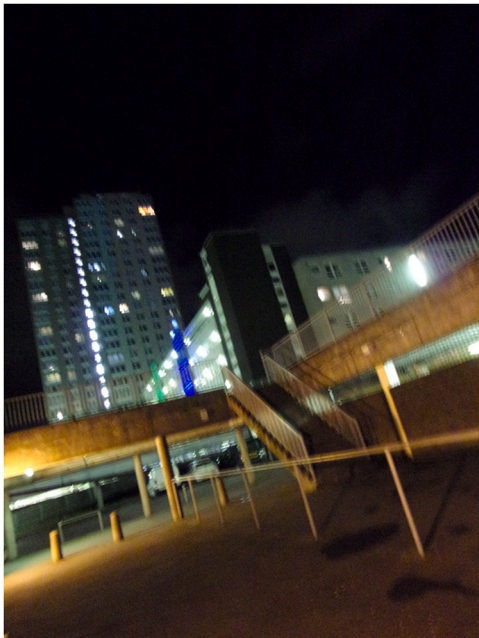
(A)

(B)

Fig. 10. Photovoice images taken by Liz of her neighbourhood at night-time ©Dying in the Margins 2022 all rights reserved

Fig. 11. Photovoice image taken by Liz of the public library she used as a 'warm bank' ©Dying in the Margins 2022 all rights reserved

Fig. 12. Professional portrait of Amandeep in the hospice ©Margaret Mitchell 2022 all rights reserved

sense of self and of home. When Liz had no choice but to move to a hospice for the last month of her life, she was not able to personalise her room, which was something she had worried about: "I cannot face being in a hospice with no visitors at all. I can see that happening. And no access to my stuff." Fig. 15 shows the few belongings which accompanied her to the hospice which stand in sharp contrast to the colour and flamboyancy of the belongings in her flat.

Another aspect of individual identity which tied people to their homes was their pets. Max, for example, was very focused on staying at home so he could remain in the company of his Jack Russell, Lily. It is likely that Max, who according to his friend and carer had undiagnosed PTSD, gained significant therapeutic benefit from having Lily near him. Fig. 16 shows a photograph taken by Margaret Mitchell of Lily sitting protectively on Max's legs at home on his sofa, while on the right is the replica china Lily which Max took with him each time he was admitted to the hospice but was acknowledged to be a poor substitute.

Some participants' individual and relational identities were tied to the spatial imaginaries of their homes regardless of whether their property was being properly maintained, the stress of paying bills, or whether it was considered "cluttered" by professionals. Participants derived considerable therapeutic benefit from home-making activities,

home comforts, and companionship, which supported people's identities into the dying phase of life. Some also derived benefit from taking photographs for the study as well as by being photographed by the professional photographer [see (Richards, Quinn, Mitchell, Carduff, & Gott, 2023) for a fuller discussion].

4.4. Home and autonomy

Our data showed that being at home enabled some of our participants to maintain their sense of autonomy. By autonomy, we refer in the broadest sense to a capacity, state, or right to individual self-government (Colburn, 2022). More specifically, the exercising of autonomy can be viewed as a form of self-authorship where the person decides for themselves what is valuable to them. Some of our participants felt constrained by the hospice environment in terms of their ability to engage in forms of expression and action which provided a sense of control. Being able to decide their movements, for example, was deemed important and they felt restricted in this capacity:

> [the hospice] lock the doors at 10 o'clock at night and you're locked in [...] and they don't get opened until about 10 or 11 in the morning, and I'm demented [...] in fact, I was going home at first when I couldn't get the scooter, and I says, "I cannot sit in this room." [Margaret]

Here, Margaret expressed a sense of feeling bored ("demented"), trapped and generally unable to do the things that she wanted to do. Fig. 17 (below) shows Margaret in her room at the hospice.

Max expressed a similar sentiment to Margaret:

> I prefer being at home. No one wants to be in a hospital. I want to do my own thing.

At a certain point, Max's desire to be at home and to "do his own thing" led to a dramatic "great escape" from the hospice (Quinn, Ferguson, Read, & Richards, 2024). According to his friend and carer, Max had a history of trauma and undiagnosed PTSD from serving in the army, and he found institutions oppressive. It is well established that poverty and experiences of trauma have strong correlation (Allen et al., 2014) and that people with experience of trauma, like Max, can have negative associations with institutions, including health care institutions, and can react badly when spending time there (Giesbrecht et al., 2018).

For other participants, capacity for self-government was determined in their own mind by access to, and control over, their own (limited) income. The desire to remain at home for as a long as possible was linked to the need for sufficient funds to be able to do so, and personal discretion over those funds. Some participants, for example, were keen to impress on the researcher their history of financial independence and of not previously needing state support to get by:

> Sometimes it feels like begging for money as I have always been fiercely independent with money and never asked anyone for handouts. But my needs now mean I must swallow my pride and apply. [Marie]

Margaret, on the other hand, wanted to access her state pension so that she could leave a more secure financial legacy for her dependent daughter:

> I've never claimed unemployment benefits ever. Talking about national insurance stamps, I'm fully booked up. I'm going to lose my old-age pension, which I never, ever received in the first place and everything is going to be left. [Margaret]

These participants were looking for state support to maintain the financial independence that they were accustomed to, albeit a precarious independence. Paying their own bills, supporting dependent children, and securing their financial legacy while living their final months at home was important to them because it manifested a degree of self-authorship.
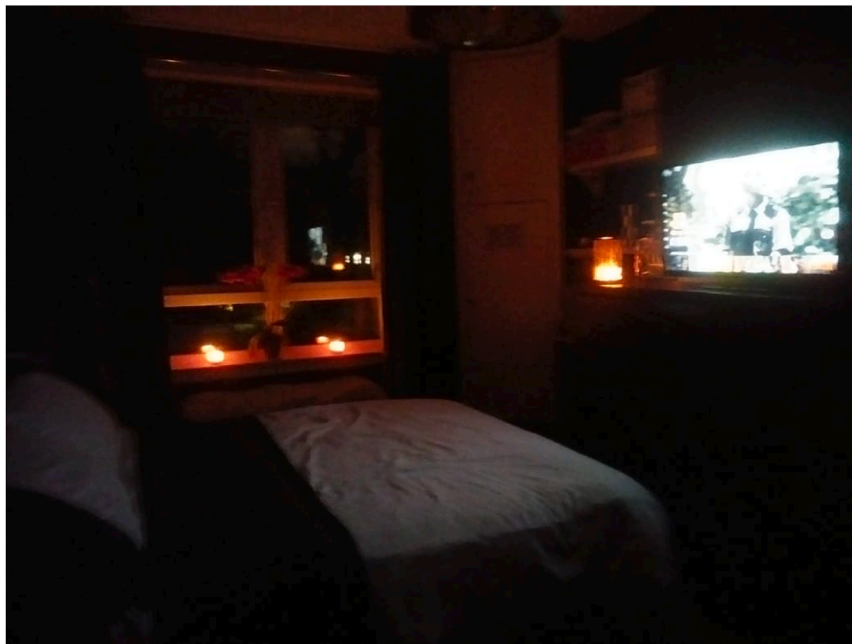
(A)
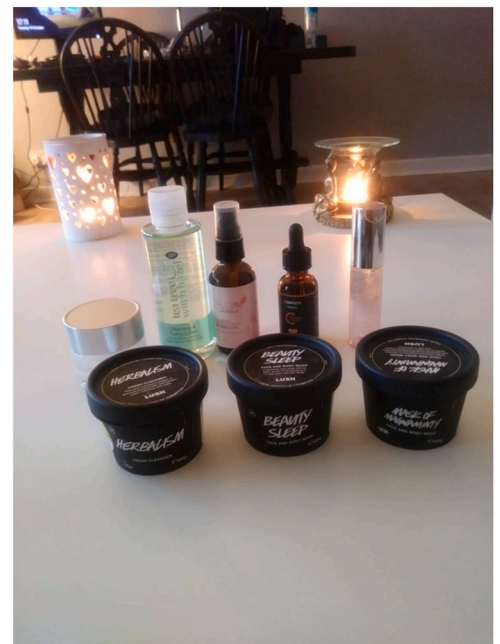
(B)

Fig. 13. Photovoice images taken by Marie showing her bedroom and pampering "treats" ©Dying in the Margins 2021 all rights reserved

(A)

(B)

Fig. 14. Photovoice images taken by Liz of her clothing ensembles ©Dying in the Margins 2022 all rights reserved

A final point about autonomy and home dying when experiencing financial hardship was the role of unpaid carers for enabling and maintaining people's autonomy. Almost all theories of autonomy acknowledge that relations with others have an important causal effect on whether or not someone is autonomous (Colburn, 2022). After Max's

elopement from the hospice, it was his two friends who undertook to care for him in his flat, as per his wishes (see Fig. 18). However, while people can be dying "at the margins" of the safety net provided by the state, there is also caregiving "at the margins" where caregivers are themselves struggling with various intersecting disadvantages

(Stajduhar et al., 2020). While the financial and emotional strain on lay caregivers is well established, there has been less focus on, and less recognition of, the ways in which those strains may be exacerbated by financial hardship and material deprivation (Gardiner et al., 2020). In our study, caregiving was sometimes attenuated by the multiple hardships which our participant's closest friends and relatives were living
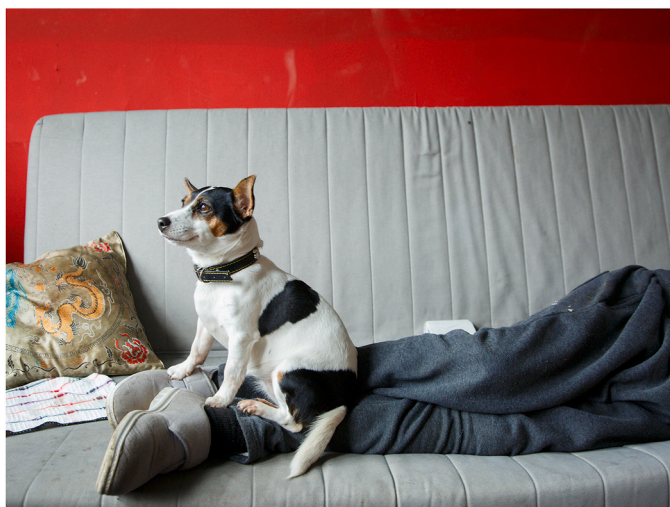

Fig. 16. Portrait photograph of Max's dog Lily at home and a Project Diary image of a china replica of Lily in the hospice where Lily not permitted to stay ©Margaret Mitchell 2021 all rights reserved

with and managing. And when our participants key supports faltered, their capacity for autonomy also diminished.

5. Discussion

There is an 'equity turn' currently underway within palliative and end-of-life care research and policy, which is focused on highlighting the end-of-life care and support needs of structurally marginalised groups within society (Richards, 2022; Stajduhar & Gott, 2023). While our study was focused specifically on experiences of financial hardship and deprivation at the *end-of-life*, our data also supports what is already known about how disadvantages are multiple and intersecting and they can reverberate across the life course (Marmot et al., 2010). The fact that only one of our participants had reached retirement age by the time of their death supports what the quantitative literature tells us: that those with experience of poverty across the life course die at younger ages.

In our study, we were focused specifically on people's perceptions of, and experiences in, their home environment at the end of their lives. It is increasingly recognised that, up until now, insufficient consideration has been given to the social and, crucially, *economic* capital required to

Fig. 18. Professional portrait of Max and his friend/carer with Lily the dog at home ©Margaret Mitchell 2021 all rights reserved

support home dying, and to how the material environment of the home, which varies across the social gradient, impacts end-of-life experience. Participants images and interviews revealed a variety of factors affecting people's capacity to remain at home, notably the high financial costs in the form of electricity, heating, equipment, taxis and private care costs. These costs were noted by participants to be "sky-rocketing" due to the 2022 energy crisis and inflationary pressures. Some of our participants were entirely dependent on state welfare payments to cover these costs and therefore on finding a welfare benefits co-ordinator who could advocate for them and maximise their entitlement to state support, which didn't always happen.

While there is some criticism in the literature that the values and qualities which are ascribed to home - privacy, intimacy, warmth, comfort, security and autonomy - are predominantly middle-class (Blunt & Dowling, 2006; Pollock et al., 2023), our findings show that even for people living in more materially deprived circumstances where security and warmth were lacking, home *still* embodied some of these valued qualities and was central to wellbeing, as reported elsewhere (Garnham et al., 2022). The home environment was particularly valued as a site for identity-supporting activities and enacting autonomy, and some participants were explicit about wanting to die at home. This prioritisation of home at the end-of-life even within the context of poverty and poor-quality housing indicates that the symbolic value of home extends beyond both its economic or material value. As such, it is our view that discourses which suggests that there are some homes which are 'unsuitable' or 'not conducive' for palliative care delivery, and thereby unproblematically equate material with symbolic unsuitability, need to be questioned (All Party Parliamentary Group on Terminal Illness, 2021). It may be that enabling people to remain at home and "scaffolding" their autonomy (Anderson, 2022) through, for example, adopting a trauma-informed approach which seeks to make palliative care delivery more flexible and responsive (Quinn, Ferguson, Read, & Richards, 2024), becomes even more important and something which care providers could better support and advocate for.

However, both inside and outside the home, participants experienced material issues with their housing, a finding in line with international evidence that people experiencing poverty are most at risk of living in sub-standard housing (Braubach & Fairburn, 2010). There were difficulties navigating multiple flights of stairs, broken lifts or lifts which didn't reach far enough, run down neighbourhoods, poorly maintained flats, and cramped conditions. Our participants resided in social rented, private rented and mortgaged properties. For those living in social

rented housing, home adaptations and maintenance were not undertaken in a timely way (MND Scotland, 2022); systems were unresponsive and interactions with housing officials could leave people feeling unheard or even blamed for their circumstances. It is clear from our study that awareness-raising about the fact that people are living out their dying at home, in community, and are not just sequestered away in institutions is currently needed in the housing sector (see also Hansford et al., 2022). Housing providers also need to take account of the fact that in more deprived areas, tenants will experience more life-limiting illnesses at younger ages (Marmot et al., 2010) and therefore should be wary of designing policies or granting access based on chronological age.

As our participants neared death, their ability to self-advocate for changes to their material environment, for the appropriate statutory care supports to be put in place, and for healthcare professionals to truly recognise the social determinants of health, diminished. People nearing the end of life could benefit from a targeted advocacy service to help relieve some of the 'bureaucratic pain' (Downing, 2006) of liaising with housing and social security officials when they have limited time left alive. It is noteworthy here that even *with* specialist palliative care input, participants in our study who wanted to die at home were still unable to do so. This suggests that until home care services are better resourced, housing associations and landlords become more responsive to the needs of those dying in their properties, and fewer judgements are made about the "suitability" of homes for delivery of palliative care, there will continue to be a need for in-person institutional care for those experiencing multiple intersecting disadvantages.

Finally, our study indicates that moving from equity-promoting rhetoric to action, will require a strong commitment from the various sectors involved - health, housing, social care, social security, and the third sector – to take a whole-system approach to delivering equity at the end-of-life. There are certainly practical policy initiatives which can (and indeed are) being pursued in the UK and elsewhere, such as help with transport costs, increasing the size of energy grants, mainstreaming the principles of trauma-informed care, prioritising people with a terminal illness for housing maintenance and adaptations, and accelerating access to the state pension for those who are terminally ill. However, the elephant in the room here is the neo-liberal political context and the resource constraints which affect how much, as a society, we are prepared to redistribute to those who are worst off and in greatest need at the end of their lives.

5.1. Limitations

Our study coincided with the COVID-19 pandemic and this compounded some of the known challenges of using participatory methods, recruiting people who are at the end-of-life, and recruiting people who are structurally marginalised. In addition, we experienced significant challenges recruiting through GP practices, resulting from a combination of: the systemic pressures caused by the pandemic; inexperience with the type of study proposed; and a suspected discomfort in approaching people about both end of life and poverty (Quinn, Richards, & Gott, 2023). Therefore, most participants were recruited via two hospices. This meant they were in receipt of specialist palliative care, which makes our sample unusual given the evidence that people living in areas of higher deprivation are less likely to access specialist palliative care in the last year of their life (Davies et al., 2019).

6. Conclusion

The number of people experiencing poverty in the UK is on the rise, as a result of the COVID-19 pandemic, the cost-of-living crisis, and government cuts to public services (Brewer et al., 2023). At the same time, the UK, like other countries around the world, is also experiencing an increase in the (total) number of people dying resulting from as increasing in population, which is set to continue in the forthcoming

decades (Marie Curie, 2023). Both these trends combined means that the number of people dying in a context of financial hardship and deprivation is increasing.

This participatory, visual methods study is the first of its kind to document people's experiences of dying in the UK in conditions of financial hardship and deprivation. We found that both individuals who are dying, and their carers, are currently being poorly served by unresponsive healthcare, housing and welfare systems which are insufficient to facilitate a high-quality home dying experience. Our participants social circumstances were shown to cause them significant distress, including: insufficient income; housing and neighbourhood issues; the shaming effects of poverty; and the lack of recognition given by state officials. Our findings also show that dying at home can still be the preferred option for people who are struggling to make ends meet, as it links to people's sense of identity and autonomy. However, it is not always a viable option.

At present, inter-sectoral initiatives spanning healthcare, housing, social security, social care, and the third sector which might make a difference to the social determinants of dying, and enable home dying across the social gradient, are few and far between internationally (Stajduhar & Gott, 2023). Findings from this study lend further evidence in the push for equity principles to be mainstreamed and for inter-sectoral initiatives and additional investment to be focused 'on the margins', where there is greatest need.

CRediT authorship contribution statement

Naomi Richards: Writing – review & editing, Writing – original draft, Supervision, Project administration, Methodology, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Sam Quinn:** Writing – review & editing, Project administration, Investigation, Formal analysis, Data curation. **Emma Carduff:** Writing – review & editing, Funding acquisition, Formal analysis. **Merryn Gott:** Writing – review & editing, Methodology, Funding acquisition, Formal analysis, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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