Unpacking the impact of older adults' home death on family care-givers' experiences of home

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Abstract

Public Health England survey data indicate that while the place of death is geographically uneven across England, given a choice, many older people nearing end of life would prefer to die at home (2013). There is, however, a growing critique that policies designed to support home death fail to understand the needs and preferences of older people and may not be regarded as an appropriate option by those most closely involved. Home death relies heavily on the willingness and availability of family members to provide the required care. There are, however, major gaps in our understanding of how care work undertaken by family members within domestic settings may create tensions between home and care that fundamentally disrupt the physical and socio-emotional meaning of home for carers. This can have consequences for their own well-being. In this paper we draw on interview data from our 'Unpacking the Home' study to elicit an in-depth understanding of how facilitating a home death can create an ambiguity of place for family carers, where the issues faced by them in caring for a dying older person at home, and the home death itself, can fundamentally reshape the meaning and sense of home.

Highlights:

- the study identifies the paradox of 'whose home' in relation to the home death

- disruptions to the meaning of home following a home death can result in that 'home' becoming a 'house' for carers

- carers need better support post-death, especially those still living in the home where death occurred

Background

Providing quality care at end of life and understanding where best that care should take place has been high on national and international agendas for over a decade (WHO, 2004; Venkatasalu et al, 2014; Morris et al, 2015). Within the research community this political drive has resulted in a growing interest in what underpins and supports decisions around place of death (see for example, Grundy et al, 2004; Macnamara, 2007; Cardenas-Turanzas et al., 2011; Luckett et al., 2013). Commentators suggest that this spatial turn has been part of an international move designed firstly, to reduce hospital stays and increase community support to facilitate the home death; and secondly to address the growing demand for patient and family choice (Higginson et al, 2013). Evidence emerging from a number of systematic reviews suggests that home-based palliative care not only results in greater caregiver and patient satisfaction, but reduces the length of hospital stays, so increasing the likelihood of home death (e.g. Finaly et al, 2002; Gomes and Higginson, 2006; Shepperd et al, 2011). However, whilst a desire to increase patient and family choice may, in part, underpin this shifting agenda, commentators also maintain that the drive to increase the numbers of home deaths cannot be entirely divorced from concerns around cost containment (McNamara, 2007; Seymour et al, 2007). Evidence about the benefits of home care at end of life is also conflicting, although recent reviews suggests that the holistic well-being of the dying person may be greater at home (Donovan et al, 2011; Higginson et al, 2013). While there is clearly some debate around what underpins the changing emphasis on place of death, it is, nevertheless, an agenda that has international traction. This is a debate that is not only of relevance to palliative care stakeholders, but one that extends more broadly to public health due to the rising numbers of home deaths and increasing health expenditure (Higginson et al, 2013).

Despite an international policy drive to encourage home over institutional deaths, researchers have demonstrated the existence of significant social and spatial variations in the extent to which it has succeeded in its aims (e.g. Cohen et al, 2008; Pinzón et al, 2011). Geographically, the numbers of home deaths rose in North American countries during the 1990s and first decade of the 21st century, but this pattern was not mirrored in Europe where numbers in many countries were seen to fall. In the UK however, there has been a slight increase in home deaths since the introduction of the End of Life Care programme in 2004 and the subsequent End of Life Care strategy in 2008 (Jack et al, 2013). Indeed, one recent Public Health England report in 2013 noted that the proportion of home deaths in England has increased from 38% in 2008 to 44% in 2013. Whilst recognising that spatial variations exist within countries, Higginson et al (2013) also suggest that similar shifts in national policies around end of life care in other European states could increase choice around place of death, leading to a similar upturn in the numbers of home deaths. But policy shifts are only part of the story, evidence points to a wide range of factors associated with the likelihood of achieving a home death including affluence, culture, ethnicity, patient preference, complexity and speed of disease progression, availability of home-based palliative care and family support and age (Seymour et al, 2007; Jack et al, 2013; Higginson et al., 2013). Older age is also a factor – UK data illustrate that while hospital is still the mostly likely place of death for older people (61% of deaths of those aged 65+) this is followed by the older people's own home (21% of deaths of those aged 65-84 years), at least until late old age (85+) when deaths in nursing homes overtake the numbers of those occurring at home (NCIN, 2010).

Conceptualising home and the home death

Where we spend the most important moments of our lives is a relevant issue to all (Higginson et al, 2013). Geographers, gerontologists and sociologists have all attempted to theorise the nature and sense of home, placing emphasis on the home as a key site in which many of these important moments in our lives are played out. Through this lens, home is understood not just as a physical structure, but as a place that is imbued with multiple meanings linked to identity, safety and security, privacy, power and control, emotion, nurture and historical memory (e.g. Chapman and Hockey, 1999; Twigg, 2000; Milligan, 2000, 2009; Imrie, 2004; Blunt and Dowling, 2006; Langstrup, 2013; Collier et al, 2015). Our sense of home and the affective bonds that develop between people and their homes thus relates to both the intrinsic character of the home itself, and /or the meanings people attribute to it.

In considering the significance of home as the preferred place of death, Williams (2004) maintained that for many, the familiarity, physical arrangements and habituated routines within the home imbue it with a sense of comfort, security and ease; this can be important not just for the dying person, but also for family carers who are faced with the emotional upheaval of impending death and the sense of helplessness this can engender. We should not forget however, that people's experiences of home are both relational, co-produced by the key actors, actions and objects within it, and temporally situated, in that the complex socio-spatial relations of home can shift and alter over time. So, whilst claims for home as a place of ease, comfort and security etc. may well hold true for some people at some points in their lives, as Brickell (2012) points out, we also need to recognise that interpretations of home are often eulogised. Such interpretations can ignore or overlook the ways in which the home can, at different times, be a place of stress, loneliness, fear, neglect or confinement. Our sense of who and what we are is, thus, continually shaped and reshaped by how we feel *about* home

and how we feel *in* the home. This may relate to an individual's unique experiences of that setting, or involve the mediation of others through intersubjective experiences of places. Our emotional relationship to the home can thus alter the way the world *is* for us and feelings associated with the home are an integral component of an individual's spatial experience. In her work of family care-givers experiences of older relative's care transitions from the family home to care home settings for example, Milligan (2004) points out that whilst homecare provision can create tensions around how family carers feel *in* and *about* the home, these are not necessarily resolved once the transition to a care home setting takes place. Indeed, she suggests that the transition from home to care home can be akin to the emotional experience of bereavement, without the closure of death, but with a similar impact on the family carer's sense of home. Brown's (2003) work on home hospice too, drew attention to the emotio-spatial paradox of home arising from the home death.

To date, however, most of the literature on home death has focused either on geographical and statistical variables related to the incidence of home death, or on specific disease categories (e.g. cancers) as the main causal factor. Further, the focus has been on adults rather than older people whose end of life experience is often underpinned by varying and multiple health issues (Gott et al, 2008). With a few exceptions, this work has tended to focus on the experience and desires of the person facing end of life themselves rather than those of family carers. Whilst this is, of course, understandable, it is important to recognise that without the support of the family carer, home death is unlikely to be an option. Yet research that addresses family caregivers' experiences of the home death is relatively limited (Topf et al, 2013). One recently published review of family carer's perspectives of home care provision at end of life, highlighted not only the need for good qualitative studies that explore the meaning of home across the caregiving process, but also the extent to which the experience of

care-giving can alter family carers' perceptions and attachment to home (Morris et al, 2015). We would add that there is also a need for good quality studies that address the extent to which these micro-geographies of death and dying alter the family carers' relationship with the home not just during the dying phase, but post death. In this paper we seek to go some way toward addressing these gaps by drawing on qualitative data from our 'Unpacking the Home' study to focus firstly, on unpicking assumptions within policies around home death regarding whose home that end of life care is being performed within and why; and secondly, on how the home death of an older family member impacts on the meaning and sense of home for the family care-giver post-death.

Research Design

Our paper draws on data from a two year cross-sectional qualitative study designed to gain an in-depth understanding of the experiences of family carers who were caring for a dying older person at home. In particular we were interested in the extent to which this impacted on carers' experience of home both pre and post death. The study was conducted by a multi-disciplinary team combining skills from primary care; nursing; health psychology; sociology and health geography and undertaken in two locations in England, the North West (Lancashire and Cumbria) and South West (East Devon). These regions were selected as both have high proportions of older residents and whilst located at opposite ends of the country, they have similar geographical characteristics. Both regions comprise a mix of rural and remote areas as well as large areas of coastline. With the exception of the town of Blackpool and city of Lancaster in the North West, most urban areas in both regions comprise relatively small towns (population > 40,000 people) and villages (ONS, 2015). They do, however, have different socio-economic profiles with higher levels of deprivation in the North West,

particularly in towns such as Blackpool and Morecambe, in comparison to the higher levels of affluence in East Devon. There are also concomitant variations in health indices including obesity and smoking rates (high in North West, low in South West) Public Health England, 2015).

Study participants comprised bereaved family carers purposively recruited through GP practices for two reasons: firstly, the practice checked the appropriateness of inviting a potential participant based on their knowledge of the family and the circumstances surrounding the death; and secondly, to ensure confidentiality of patient information was maintained. The practices identified potential participants meeting the criteria (see Table 1 below) through their patient databases. In practice, this meant searching for patients who had died at home within the time frame of the study, and identifying the main carer; only those whose main carer was also registered at the same practice were included. The initial invitation therefore came from the GP, on behalf of the research team, with invitation packs being sent by the practice to those expressing an interest in participating. Potential participants were then asked to contact a member of the research team to discuss the study and arrange an interview if appropriate. Initially we sought to recruit only those aged over 65 years; difficulties with recruitment led us to reduce the age criteria to those over 50 years in order to widen the potential pool of participants (50 years and over being the age many third sector organisations use to define 'older people'). Interestingly, despite these initial difficulties, the average age of our final sample was over 71 years.

INSERT TABLE 1 ABOUT HERE

An in-depth interview was conducted with 59 bereaved family carers who met the criteria, with the aim of eliciting their experiences of supporting the home death of an older family member - both before and after death. Thirty six participants were located in Devon and twenty three in Lancashire and Cumbria. As Table 2 illustrates, the vast majority of participants were women (N= 41 women versus N= 18 men). This gender difference is reflective of the fact that, overall, women are more likely to undertake care than men (ONS, 2013). Family care-givers' backgrounds, as indicated by occupational status, varied widely - from cleaners and housewives through to company managers and clinicians (see Figure 3).

INSERT TABLE 2 ABOUT HERE

Only 5% of our total sample came from Black and Minority Ethnic communities: white non-British (N=2); and Afro-Caribbean (N=1). The overwhelming majority of participants were white British reflecting the ethnic make-up of these two locations (Census 2011, Office for National Statistics).

While there was some difference in the length of time people had been caring for their older family member, on average participants had been undertaking their caring role for 2.5 years. Cause of death varied, the majority were reported as dying from differing forms of cancer (N=36); others were variously reported as dying from heart disease/stroke (N=9); neurological conditions such as dementia or Parkinson's disease (N= 7); 'old age' (N=4); renal failure (N=2) and rheumatoid arthritis (N=1). The age range of carers participating in this study was between 54-90 years with the median age being 71.3 years; the age of those cared for at time death ranged from 59-98 years, with the average age at time of death being 79.8 years. Further details of carer and cared for characteristics are contained in Table 3.

INSERT TABLE 3 ABOUT HERE

The interviews were designed to elicit chronological accounts of family carers' experiences of the home death. In part, we sought to understand what forms of practical, social and emotional support made the home death possible and the deficits or gaps in that support. However, we also sought to identify how the socio-emotional space of the home is experienced and performed by family carers, both during the process of care-giving at end of life and in the early post-death period (up to six months post-death). Interviews were around an hour in length, were digitally recorded and transcribed in full. In all but three cases (all occurring within the home of an adult child), care-giving was undertaken within the home of the dying relative.

Two researchers (MT and SB) undertook the interviews (one researcher per location) using a common set of interview themes. A cross-sectional thematic analysis of the data was then undertaken. An iterative approach was used, with an initial framework of thematic categories applied to interview data drawing on the research objectives. The thematic categories and framework were developed and agreed by the whole team. A process of constant comparison was also undertaken to ensure that the early stages of analysis informed subsequent data collection and emergent issues were pursued throughout the research process.

Ethical approval for the study was awarded by the National Research Ethics Service (NRES) Committee North West (Ref: 11/NW/0203) and the norms of good ethical practice in research were applied throughout the conduct of the study.

One aspect of our study sought to unpack the impact of the home death on family care-givers both pre and post death. Following analysis, it was evident that in terms of the pre-death experiences, our data simply reinforced already well documented findings. That is, that family carers can be exposed to a wide range of physical, social and emotional challenges when undertaking home based care that can impact on their sense of home and that these experiences can be exacerbated when the cared-for person is approaching end of life (see for example, Carlander et al, 2011; Donovan et al, 2011). While this, of course, is a finding in itself, there is limited value in reiterating these findings here. Instead, we turn our attention to the more novel elements of our findings to focus on two core issues: firstly we draw on our data to challenge assumptions about 'home' in relation to the home death. We discuss the neglected area of whose home that care takes place in, and what this means in terms of claims made about the meaning of home in supporting end of life care. Secondly we discuss how home death impacts the spatio-emotional experience of home for family carers, and the implications of these experiences for the meaning of home post-death.

Findings

Whose Home?

Work focusing on the importance and meaning of home for end of life care has tended to overlook the issue of whose home that care takes place in, how that impacts on the meaning and sense of home, and for whom. Within our study, sixteen family carers were non-spousal/partner carers. Thirteen of these undertook care within their dying family member's home, the remaining three undertook care within their own homes. Issues of distance, work, family relationships, other familial obligations or the availability of wider networks of care and support all played a deciding factor in negotiating within whose home end of life care would be delivered. As one adult son noted:

> *A31: there was no way that she could look after herself, so I said that I would stay up there the week, or for how long, to look after her…. and I rang* [J] *after two days, and said, 'Look, you know, this is ridiculous. …' I couldn't take any more time off work as such, 'We'll have to bring her* [mother] *home.'*

Balancing care and work responsibilities played an important role in some family carers' decisions about where the home death could be supported. For some, this was also linked to a pre-planning of care and support for a dying older relative when the practicalities of undertaking care from a distance would become unmanageable. Our analysis revealed examples of adult children encouraging an older parent to live independently but in a location closer to their own home (often downsizing at the same time and moving to single level accommodation such as a flat or bungalow), moving the older family member into an annexe attached to their own home, or into their own home itself. As one adult daughter commented:

> *B03:   …well my mum and dad moved in to live with us in millennium year, because my dad had peripheral neuropathy, and erm he was going gradually downhill and*

obviously my mum was getting older and finding it harder to look after him… then we suggested that if they needed, they could move in with us, cos we've got a place through there, they have their own lounge, their own bedroom, their own bathroom really 'cos we had an ensuite, so they did that.

I: So you had plenty of room?

B03:   erm yeah so they lived with us since then, and then my dad just got worse and worse obviously and eventually ended up in bed didn't he?

Husband: Yeah they lived in south [city], *so every time you know there was a problem B03 was having to go down on the motorway, and that was inevitably going to get worse and worse and she was going to have to go more and more so that was really the reason wasn't it?*

For others, particularly those who were themselves lone-dwellers, their own retirement, changed personal circumstances or issues of practicality, such as the suitability of the home for facilitating care, sparked a decision to move closer to, or into, the parental home. One adult daughter noted:

B15: …..it's only because I have no husband, I have grown-up children, I have no commitments, I had no job… I'd retired… and no pets, nothing. So I said I would move in with him [father] *… I couldn't bring him here* [own home]. *Down there he had a walk-in shower. He had a bigger place than this even though it was just a flat. He had a lovely big room and I could put this camp-bed out in his sitting room.*

Understanding 'whose home' is being referred to in the home death was further complicated by evidence of adult children moving back into the parental home and purchasing it from their ageing parent/s who then continued to dwell in the home with the adult child. As one adult daughter revealed:

B18: .....I lost my son at the age of 14, so I sold up my property and went to live with Mum and Dad. Then I bought the bungalow off Mum and Dad to get back on the property ladder and then I met my now husband, so the four of us ended up living together because we'd had quite a lot of extensive work done to the bungalow. So we were all there anyway.

For others, supporting a home death within their own home can be unplanned, and arise as consequence of a breakdown in what had previously been a satisfactory care-giving arrangement undertaken by other family members. As one adult daughter revealed:

A12: Well my mother had a long term heart problem, she lived at the top of a hill, she lived in the same house where we were all brought up, sixty years. And we all panicked because she was getting out of breath and so on. So my sister bought her a house in [Town1] *in* [County1] *which was where my sister lived, and she* [mother] *lived in that house by herself but* [sister] *was quite close by and my niece was quite close by, and they used to drop in and do her shopping and take her out and so on. So that was going on for a while and then mum started falling, and basically my sister was working part-time and had to keep going to take time off to take mum to the surgery and all the rest of it, and it really got a bit nasty and there was a tremendous blow up which was most unfortunate, and in a totally unplanned and unpleasant way she came down to us. And she'd been staying with us for about 6 weeks, and we took her back and my sister was in* [County1] *at a Christmas market, my brother-in-law was there and he said that it*

was just, they just didn't, he didn't, want anything more to do with it - and my sister wasn't there. So we said right, so we turned round and brought her back, and it was very unpleasant and poor mum was terribly shaken up cos it wasn't like saying you know this doesn't seem to be working, perhaps we ought to work something out you know? It was just a slam in the face really. And so she came to live with us and that was that ...

Each of above examples raise an interesting paradox around the home and the complexity that underlies claims made for, and attempts to understand, those attributes of home deemed to be supportive of the home death. In particular, they raise questions about for whom claims around the meaning of home are being made. Related claims about the home as a site of familiarity, habituated routines and physical arrangements that facilitate privacy, power, control and historical memory that can be supportive for a home death are thus drawn into question. Where end of life care is delivered within the family member's home, for example, the degree of closeness of familial bonds; the magnitude of familiarity with that setting; and the norms of behaviour within it; all impact on the meaning of home for both the dying family member and the family carer. The quote above from A12, for example, reveals how the dying family member moved firstly from what had been the long-term familial home, that would have been imbued with those characteristics attributed to a sense of home, to an independent setting in a different town where she could benefit from familial support. At a time when A12 is clearly requiring additional support, she is also faced with building a new sense of home, in a new location, that is socio-spatially less familiar to her. Growing care needs and subsequent breakdown of that family care-giving, resulted in a further unplanned move to the home of a second adult child in a yet another town. This, and the other examples given above, clearly call into question the perception that a home death facilitates the ability

of the older person to 'die in their own bed'. Moving to different houses in different locations away from the familial home also raises questions about where power and control lies and the extent to which the dying relative is able to draw on the meaning of home – and relationships within - to help them truly feel 'at home'.

Where end of life care takes places within a non-spousal care-giver's home, pre-existing power relationships between the carer and cared-for can also actively reshape everyday routines, norms and sense of home. For some, good relationships with the dying family member prior to supporting a home death acted to override the difficult circumstances and considerable disruption that a home death brings to the meaning and routines of home. But this is not always the case. As one adult daughter caring for her mother noted:

> A19: … [husband] *said I should have laid the law down when she* [mother] *came with us first because Mum was domineering. She looked after her parents from the age of 19 and they died when she was 62 or 3, when she was in her sixties, and they lived across the road and she waited on them hand, foot and finger. So it was expected, but she ruled the roost with everybody, even my Dad. I mean she ruled…*

> W*: She thought then, when she moved in with [carer and husband], *that she could take charge of them.*

> A19: *She told us what we were eating every day.*

> W: *Would only have her meals at a certain time.*

> *A19: Yeah. Her meals was nine o'clock – breakfast; elevenses; one o'clock – lunch;*
>
> *three o'clock - afternoon tea; five o'clock – dinner. Oh, yeah.*

*W is cousin to A19

Whether relationships are good or bad, even non-spousal family carers can find their own sense of home disrupted as they make physical and social transformations to their own home to accommodate the needs of the cared-for. This includes making way not just for the dying relative, but also for negotiating and adapting space for those possessions deemed necessary to make them 'feel at home'. As the same adult daughter went on to say:

> *A19: … when Mum came she insisted on bringing all her furniture with her, we had a*
>
> *house-full as well, so we brought whatever she could with us. Some of it, when we got*
>
> *here, she realised she couldn't keep, but then it's clearing the room out…*

The alterations required to support a home death can also mean making way for the increased presence of professional care staff and the portable technologies and paraphernalia of care that, while disrupting the everyday rhythms and order of the home, are necessary to the provision of good care. In our study, such transformations included both permanent and temporary rearrangements of the home. For example, undertaking loft conversions and re-organising living and sleeping spaces to facilitate the dying relative's move to the carer's home; adapting rooms to create ensuite facilities or remodelling bathrooms to meet the needs of the dying relative. In addition, family carer's needed to make space in their homes for the aides and adaptations necessary to support the home death and the space required to work around them. One adult daughter commented:

B03: Well I had to empty upstairs as well didn't I? 'Cos it went through, well two hoists one over his seat and one over the bed and the one over the seat. We used the loft and I put some flooring down. We changed a lot when they [parents] *moved in really. We sort of emptied that half of the house of our stuff and they brought their own furniture, and then when he needed a hospital bed we had to get rid of a bed.*

The technologies and service arrangements required to provide home-based care can result in an institutionalisation of the home that impinges on both the family carer's and dying older relative's sense of home (Milligan, 2009). Carers in our study revealed how they were required to reorganise the home to make way for a wide range of portable technologies such as airbeds, wheelchairs, hoists, commodes, urine bags and bottles, swabs, catheters, syringe drivers and so forth. Yet whilst our evidence does indeed point to home death as creating an institutionalisation of the home, it was also clear that family carers – whether spousal or other close relative - sought to minimalise this, creating as much order and normalcy within the home as possible. As one adult daughter noted:

B02: Well erm I could kind of secrete them away, anything like that into that other room, which I just kind of used as a storeroom. But that wasn't so good because I tried to keep things very, very tidy, because there was pads, urine bottles, urine bags, gloves, swabs, everything all over the place you know, so I just tried to keep it all tidy as much as I could.

Perceptions of home post-death: from home to house?

Whilst much of the literature on family care-giving and the home focuses on experiences of home during the care-giving phase, we also sought to understand how the home death impacts on family carers' experiences of home post-death. The literature on care, home and older people highlights its importance as a site of historical memory and identity (e.g. Angus et al, 2005; Milligan, 2009; Brickell, 2012). Post-death, this can involve the purposeful retention of artefacts that hold meaning in the construction and maintenance of that memory, sometimes despite the benign intentions of other family members. As one spousal carer revealed:

> *A04: It will have to be changed and she* [sister] *wants to get a new suite of furniture for me erm but I'm not getting rid of his chair at the moment erm I'll do it in my own time, I think they mustn't force me. I will not get rid of his chair for anything mmm hmm and I've still got this feeling, this is why I don't want to be away in hospital for long, and I've got to get over it, I've just got a feeling ..'cos he did love it here and I think he might come back erm and I've got to be here if he comes back because I'm always here so I'm never away ... I know he won't come back but he might be back here in spirit mightn't he* [starts crying]?

Yet our narratives revealed a mixed picture where, for some, it also provided an opportunity to remove 'artefacts of discord', to change décor or the usage of rooms. As one spousal carer noted:

> *I: And have you changed anything?*

> *A13:   I've changed a lot*

I: Have you?

A13:   Yes and I'm having my tea set that [husband] *couldn't stand with flowers on that's been in that cupboard for years, I'm using that and the one that he liked, the Poole pottery one that he said we always used all our life, that went today. So that's a yes.*

Importantly, our participants' narratives highlighted the ways in which home was constructed not just as a physical structure, but as a site of personal and socio-emotional relationships. The death of a spouse irrevocably changed the nature of those relationships. For some this was manifest in a shift from 'home' to 'house'. By this we mean that for the family carer, the home had become devoid of those personal and emotional relations that were an important component in the construction of the meaning and sense of home that they attached to that setting. This was particularly the case amongst spousal/partner carers. For some, this resulted in a desire to move and recreate a new home and a new life – one that was not laden with socio-emotional experiences and historical memory that had become shadowed by loss and loneliness. What underpins this shift from home to house is well illustrated through the narrative of one spousal carer who noted:

B19: ...You know, it's nearly a year now and... it is still our home, but when I come home now it's a house and... I don't know, it hasn't been sold so I... well, we're thinking now that we'll have it rented, and I'm going to move. I think the worst thing is that I have to pack up all these things that we moved in here together and I think that's going to be the worst thing, but it doesn't feel... I don't want to stay here. I don't want

to be here… and that's why I went to work. I need to get this place out of my system.

We built this, our home, together: we did that for 30-odd years, and so I just have to…

get my life going again.

Moving to a new home of course is a major undertaking, one known to have the potential to contribute adversely to mental well-being (e.g. Morse, 2000); not all either want, or feel able, to undertake this task. Hence for others, efforts to recreate a *new* sense of home post-death involved an alteration in their spatial practices and engagement with the physical space of the home. For some, this involved the decision to avoid those spaces within the home most associated with the home death. As one spousal carer commented:

A06: I mean I never go upstairs now I live in this, I live in this room and the bedroom I don't go in, I don't hardly go in the sitting room I just walk through it.

For other spousal/partner carers, it involved rearranging the home as they sought to retain, but 'tuck away', those memories of home in ways that enabled them to move on with their lives. This involved recreating a new sense of home that moved away from the home as a shared site of dwelling and identity to one that allowed for the construction of new memories and a new sense of identity. One spousal carer noted:

A07: … And as the months were going on all these lovely pictures of him [husband] *I used to keep looking at, and it was making me more and more I didn't want to be here. And this particular day I just thought I've got to move them, I can't bear it anymore, and I moved all the pictures out the front. And then the sofa had never been here and that chair had never been there and the sideboard had you know what I mean I tried to move*

it so, and then I got rid of some of my - all this china it was our china anniversary - he started to buy me that and it was everywhere and I thought 'no I can't'. And I put it all in there [spare room] - *quite happy with it now, but I bought new different things for myself and made it more mine if you know what I mean. Like he was in that bedroom and from the day he died I've never left that bedroom, but I've changed it now, I've put different wallpaper on the back, I've put my bed in there now.*

The ways in which spousal/partner carers' sense of home had changed post-death was reflected in many of narrative interviews, often characterised by decisions to no longer use specific rooms (particularly the marital bedroom or the room in which the home death occurred); re-organising furniture, renovating or redecorating rooms – to the extreme end of moving to a new home. In all, these narratives were underpinned by a need to remake a sense of home in ways that moved away from one characterised by shared identity and memories, to one that facilitated an ability to move forward with their lives and which reflected their new status as lone dwellers.

Where non-spousal carers were undertaking care within their *own* homes, the issue was more of reclaiming that space which had been given over to the dying family member, but in ways that actively sought to imprint their own identity on that space. As one adult daughter noted:

A19: ... what is the dining-room now was our little bedroom because she [mother] *had the biggest room, and we'd got a double bed in there and used to walk past the end of the bed. But it was fine. We decided then to re-do the bedroom and move in and paint that room a totally different colour, which my husband chose it…he chose the colour to be totally different.*

Discussion

Much of the literature on home death focuses on why family carers opt to support a home death and how home-based care can contribute to 'the good death', but there is little work that seeks to understand how family carers' experiences of the home death impacts on the meaning and sense of home they attach to that setting (Morris et al, 2015). There is even less work that takes a spatio-temporal approach, that is, one that seeks to understand how the home death impacts on the meaning of home for family carers pre and post death. Actively supporting a home death, we suggest, is just the first stage along the spatio-temporal continuum for family carer-givers, one that is characterised by a complex network of socio-emotional factors. Whilst our findings around family members' experiences of supporting a home death largely reflect the findings of earlier studies, they also raised the far less frequently discussed issues around *whose home* that care takes place in, how this impacts on the meaning of home - not only for the dying older relative but also for family carers. Our findings also raise issues about how the home death impacts on the meaning of home for family carers post death. These issues have led us to locate our paper, conceptually, within a discourse of home and the socio-emotional meaning of home. Such conceptual insights are important given the assumptions about home that are implicit within a growing policy discourse that seeks to encourage home, over institutional, deaths.

We would suggest that where 'home death' means death within the home of a family carer rather than that of the dying family member, the meaning of home and the notion of 'dying in one's own bed' is disrupted. Whilst a 'home' death in these circumstances may be preferable

to an institutional death, assumptions about the benefits of home should not be taken for granted. Following Brickell (2012), we maintain that there is a tendency to ascribe home with a set of characteristics that are often uncritically regarded as being supportive of a home death. In doing so, both researchers and policy discourse fail to unpack the complex nature of the meaning of home. There is a paradox here, in that for both the dying older person and the family carer, the experience of home is altered, not just by whose home death occurs in, but also by the actors, objects, actions and complex socio-spatial relations attached to that home. Family relationships, the spatial setting within which these occur, and the meaning attached to this setting all suggest that in reality, 'home death' encompasses a non-institutional death that is experienced across a range of 'home' settings each with different levels of socio-emotional meaning attached to them. This can range from a home death being supported within the dying older person's own familial home, to relocation to an independent setting close to family members from whom they can draw support, or to the family carers own home.

Where home death occurs within the dying family member's familial home, the supportive characteristics attributed to home (safety, security, familiarity, historical meaning etc.) are most at play for the dying family member. To some extent, this also holds true for spousal/partner carers, though for them, the meaning of home is more likely to be disrupted by the work of supporting a home death. Though often clearly advised by healthcare professionals about what is involved and what support will be available, family carers are often unprepared for the disruption and challenges caring at end of life will make to their own sense and experience of home. Alterations to the physical structure of the home, the requirement to make way for the technologies and paraphernalia of care, interruptions to the daily rhythms of life to meet the regimes of care professionals or those of the dying family

member, and the impact on family carers' own socio-emotional engagement with the micro-geographies of home, all act to challenge the sense and meaning of home for the family carer in ways that can be contradictory and not necessarily positive. Whilst further work is needed on the impact of a home death on both the family carer and dying relative where home refers to that of the family member, our study has begun to unpack how issues of safety, familiarity, power, control and disruption can play out very differently in these settings.

It also seems evident from our study that the home death can have a significant impact on the meaning and sense of home for family carers' in the post-death period. For some, the home death brings a sense of comfort and closeness to the relative that has died, but many also describe a socio-emotional disengagement that alters their sense of home. For some this is manifest through a restructuring of their daily routines to facilitate an avoidance of those rooms associated with the home death, for others it is about altering, redecorating, or consciously 'putting away' aspects of the former shared home that are emotionally overpowering and which thus hinder their ability to move forward. The extreme end of this avoidance tactic (mainly among spousal/partner carers) can result in a decision to move to a new location where they can begin to construct a new sense of home – one that facilitates their ability to move on with their lives post-death.

In many ways we are at the early stages of conceptualising how these experiences act to shape and reshape the meaning and sense of home for dying older adults; and for family carer's ability to successfully recreate new lives and a new sense of home in the post-death period. Nevertheless, our work expands conceptually on Brickell's (2012) critique of home as some universally positive phenomena, to highlight not only the complexity of the meaning of home and for whom in understanding the home death, but also the ways in which the

meaning of home shifts and changes over time. Our work also adds to that body of literature that has begun to critique the notion that the home death is somehow better and should be promoted whenever possible. Indeed, while the home death is clearly the preferred option for many older people at end of life, and many family carers do their utmost to support this – there is contradictory evidence about the extent to which this helps or hinders the grieving process (e.g. Higginson et al 2013; Luckett et al., 2013). Whilst further work is needed, it would appear from these data that the picture is complex so whilst on the one hand family carers gaining a sense of satisfaction in 'having done the right thing', on the other, their sense of home, belonging and identity can be disrupted by the home death.

Our analysis thus illustrates how the home is a deeply nuanced and complex site of (sometimes shifting) social relations; a site of paradox, ambiguity and contradiction, where attributes are conditional, contextual and not necessarily positive. Any understanding of the impact of home death on family carers' experiences of the home both before and after the death needs to be alert to these complexities and the ways in which shifts in these socio-spatial relations can alter the meaning and sense of home for those individuals concerned. Disruptions to the meanings, objects and routines that are integral to the concept of home can have profound consequences for the emotional and material landscapes of care that can impact of family carers' own well-being.

Whilst community services are available (to varying degrees) to support home-based end of life care, policies and practices designed to encourage opportunities for a home death are reliant on family carers' willingness and ability to support the everyday care needs of their dying family member. A deeper understanding of the disruption of home arising from care and caring practices at end of life - and how family carers might be supported to minimise the

impacts of this disruption both before and after death - is crucial if we are to find ways to help to maintain their well-being and in doing so encourage choice around place of death. Interestingly, whilst we sought to draw comparisons across two socio-economically different regions, the lack of any emergent differences in people's experiences was striking. What was perhaps more striking was that even where good support packages were available to family carers during the dying phase, post death these services stopped completely, leaving carers unsupported to deal with the aftermath. Hence, if policy makers wish to increase the numbers of home deaths, more attention needs to be paid to supporting family carers during bereavement, especially where the carer continues to live in the home within which the person has died.

Limitations

One limitation of this study is that only those who responded to the invitation to take participate were included; those who had a particularly negative or difficult experience of caring may have been more likely to decline the invitation. Recruitment though GPs may also have resulted in some people, who may have wished to have participate, being excluded by the gatekeeping process. Finally, only three of the 59 participants were BAME communities, the vast majority were White British, hence we are unable to say whether the findings are generalisable to other ethnic groups. A further study looking specifically at the impact of home death on BAME carers would add further insights to this issue.

Acknowledgements

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