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



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ABSTRACT

Public Health England (2013) survey data indicates 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. There is, however, a growing critique that policies designed to support home death fail to understand the needs and preferences of older people and the impact on family carers. Such policies also make assumption about within whose home the home death takes place. Hence, there are major gaps in our understanding of firstly, where and how care work undertaken by family members within domestic settings takes place; and secondly, how it can create tensions between home and care that fundamentally disrupt the physical and socio-emotional meaning of home for family carers, impacting on their sense of home post-death. 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.

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1. 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 and Rosenwax (2007), Cardenas-Turanzas et al. (2011), and 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 carer 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; Sheperd 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 (Macnamara and Rosenwax, 2007; Seymour et al. 2007). Evidence about the benefits of home care at end of life is also conflicting, although recent reviews suggest 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

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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 noted that the proportion of home deaths in England has increased from 26.5% in 2008 to 30.2% in 2013 for those aged between 65–74 years and from 12.4% to 14.8% for those aged over 85 years (2013, p.12). 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 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).

2. 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 understandings 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 whom 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 inter-subjective 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 carers' experiences of older relative's care transitions from the family home to care home settings for example, Milligan (2006) 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., 2004). 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 carers' 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 unpacking 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 carer post-death.

3. 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

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