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Introduction

Populations are aging worldwide and this raises issues regarding where older people will receive care, and where they will die. Place of care and place of death matters in the End of Life care strategy of the Department of Health in England and Wales (Department of Health 2008; Department of Health 2017). Where people die, and where people receive care is at the core of the current End-of-Life care policy in England and Wales and 'home' as a place has evolved to be considered the place where most people want to die, and the place where most people should die (Borgstrom 2016). Many papers on palliative care and end-of-life care start with a phrase similar to 'the majority of people want to die at home, yet most people die in hospital'. It is assumed that when people speak of 'home' they speak of their dwelling, yet in research on the meaning of home it has been suggested that home can have a plethora of meanings (Mallett 2004). The implication of this is that when people speak of 'home', alongside referring to a place (Easthope 2004) they may refer to people (Bowlby et al. 1997), or a larger entity like a city, or country (Duyvendak 2011).

Recent research has questioned this notion as home as preferred place of death and scholars have argued that the numbers underpinning this idea do not hold up as many people are not being asked their preference, do not have a preference or cannot state their preference (Hoare et al. 2015). Additionally, hospital deaths, are often considered to be cold and clinical and are therefore considered 'bad deaths' reflecting inadequate end-of-life care (Pollock 2015). Since home deaths are equated with 'good deaths', and hospital deaths with 'bad deaths' this may make it difficult for people to voice alternative opinions concerning their desired place of death (Pollock 2015).

A reason why 'home deaths' are considered the gold standard is that hospital deaths are considered 'bad' deaths (Jacobsen 2017). Medical anthropologist Sharon Kaufman argues in her book ... and a time to die on dying in hospital in the United States, that the way hospital deaths are perceived are strongly influenced by public perceptions. Kaufman (2005) argues that the way death occurs in hospital is a cultural fabrication which has evolved out of a particular historic, political and economic situation. Kaufman shows the complexity of people dying in hospital and describes the interplay between doctors, nurses, patients and their family. Despite the fact that the majority of deaths occur in hospital this place is unable to shake of its bad reputation. But if, as Kaufman (2005) argues, considering hospital deaths as bad deaths is a cultural fabrication, we can change that narrative. Undoubtedly dying in hospital can be improved, but we can also improve public discourse on dying in hospital.

There are political and economic reasons that underpin the interest in place of death. Dying at home could potentially reduce the costs of care, as home deaths are significantly cheaper compared to hospital deaths (Higginson et al. 2013). However, research on place of death, mainly focuses on the importance of choice, and does not account for the 'hidden' costs of home deaths, such as the delivery of informal care (Solé-Auró & Crimmins 2014). This is mirrored in the current end-of-life care policy where much attention is given to the issue of choice regarding peoples place of death. As a consequence, 'home'

has evolved to be the ideal place of death as this represents ‘what people want’ (Higginson et al. 2013; Gomes et al. 2013). The additional motives for policy makers and healthcare professionals to reduce the cost of care does not receive much attention in public debate.

This essay is informed by research with older people (aged 85 and over) who were ambivalent about dying at home. Some older people were very vocal about their wish to ‘die at home’, yet personal experiences such as heart-attacks in public places showed the limitations of those desires and demonstrated how death can just ‘happen’ in any place, at any time. I argue, therefore that the emphasize on the importance of place of death is an unfruitful exercise and rather meaningless. Importantly, some older people did not want to die at home, but would most likely die in their dwelling.

‘Home’ as a Temporal, Diverse and Fluid Concept

The meaning of home at the end of life is diverse. On the one hand, it can signify safety and comfort, but on the other hand it can be a potent reminder of loss (Peace 2015). In social sciences, it is widely acknowledged that home is more than a physical place. Home can be a feeling or a state of mind which is not tied to any place (Mallett 2004). While feelings of home can be related to the dwelling, this does not necessarily have to be the case. Understandings of home can be attached to physical structures and range from houses, streets, neighbourhoods, cities and countries (Mallett 2004; Duyvendak 2011). This complexity of home and how people relate to it is important when thinking about ‘home’ as a place of death.

What makes a house a home are ‘homemaking practices’ (Bowlby et al. 1997; Blunt & Dowling 2006). These practices refer to habits and routines that make a house feel safe and comfortable. These include mundane activities such as cooking, cleaning and practicing hobbies. Burrell argues that homemaking is a continuous process in which people try to get control over their living space (Burrell 2014). Yet, she acknowledges that this process is often disrupted by factors both inside and outside the dwelling, such as neighbourhood noise, or other people inhabiting the living space. Frailty and decreased physical capacities can hinder (older) people in their homemaking practices, and as a consequence the dwelling may not be the ideal nor the desired place to be at the end of life (Penney 2013; Peace 2015). While there may be interruptions from the outside world, home, as used in policy language, is often understood as a place where people are unhindered in their homemaking activities, as it signifies independence and autonomy. This perceived autonomy ignores the fact that for many people their home is not a desirable or suitable place to be at the end of life (Penney 2013) or how homemaking activities may be affected by performing end of life care in the home.

Recently some studies have demonstrated the diversity of the meaning of home at the end of life (Peace 2015; Collier et al. 2015; Venkatasalu et al. 2014). As the UK has a diverse population, notions of ‘home’ at the end of life are similarly complex and varied. A study on beliefs on dying at home among South Asians living in London revealed that place of death was considered less important than being able to perform certain rituals and cultural practices (Venkatasalu et al. 2014). For many ‘home’ referred to the home land, the country they had migrated from prior to living in England (Venkatasalu et al. 2014). An Australian study suggests that using ‘home’ as a proxy for good care does not adequately capture the quality of care at the end of life (Collier et al. 2015). Researchers in this study suggest that understanding home as a fluid concept would be helpful to better meet the needs of dying patients and their families.

Importantly, throughout a lifetime people can create ‘home’ in multiple places. For example, it has been argued that people are very good at making public places like hotels ‘feel like home’ (Duyvendak 2011). Previous research has shown that people are capable of creating a sense of home in other places such

as nursing homes (Hauge & Kristin 2008), or hospices (Kellehear et al. 2009). This shows that homemaking could be done anywhere, and is not confined to people's houses.

Even if people do not move in later life, home is not a static unchanging concept, but a process that requires work. In other words, simply being inside one's dwelling does not automatically make it feel like home. Home is the complex interplay of space, relationships, the body, and time. The question to what extent older people feel at home in their current living space, therefore, needs frequent revisiting.

Aging and Dying for the First Time

While patient autonomy is valued both in the English as well as the American healthcare system (Borgstrom & Walter 2015; Kaufman 2005), Kaufman's (2005) ethnography shows that while patients and their families are included in medical decision-making, they have a hard time making decisions regarding treatment or non-treatment. An important notion that comes to the fore in Kaufman's work is that people do not know what they want in terms of care. Taking Kaufman's notion further, I suggest that the same issue of 'not knowing what to want' applies in relation to place of death. As people are aging and dying for the first time, these decisions are made on an ad hoc basis. Some people die in their own dwelling because they 'wanted' to. Similarly, people will want to die in a hospital, nursing home or hospice. I suggest that the majority of dying is happenstance, it is how life unfolds. In my research with older people in the southwest of England, their narratives included a lot of things older people did not want, because a neighbour, family member or friend had died that way. Much harder was it for participants to pinpoint what they did want. Importantly, some participants changed their narrative of what they wanted each time I visited them. While participants spoke about the loss and death of others, they were less willing (or perhaps able) to talk about their own mortality. This absence of talk about dying was unexpected given their readiness with which they would detail life-threatening events, such as strokes and heart attacks. As participant Myrtle commented (aged 88), when prompted to reflect on her own mortality: "That [dying and death] is for the future". While people may have preconceived notions on where and how they want to die, these ideas will change over time. With this in mind, the way home is understood in social science disciplines such as anthropology is helpful in accounting for and anticipating the temporality and relationality of the meaning of home.

Stories told by my participants reflect the unpredictability of dying, and the challenges older people face when ageing (and dying) in their dwelling. My oldest participant was Marie, 98 at the time of our meeting. Six years earlier Marie had experienced a stroke in her house. From being 'independent' and doing most things on her own she suddenly had to rely on other people for basic things like showering and the food shopping. Marie described the event as follows:

I was upstairs. And I came down. I knew there was something wrong with me but I could not think what it was, and I fell down and crawled across the floor and my phone was over there somewhere", [she points to another place in the sitting room], "and I dialed 999. And the girls [ambulance personnel] tried to get in. Of course I had the chain on the door and I couldn't open the door, and they could not use the key. So I managed to knock out one of the little catches on the window [in the sitting room we were in] and they crawled through the window.

Marie almost died in her own dwelling when she had the stroke. She had been able to reach her phone but she was aware that she could have been dead in her house for some time before anyone would have found her. While people were visiting her on a daily basis at the point that I met her, this had not been the case

before the stroke. Her son would ring her often, but there could have been days where no one would have visited her house or telephoned.

Marie's experience further raises the important question of the extent to which 'the home' is equipped for death and dying. The ambulance personnel were not able to enter the house through the front door and were delayed in helping her. However, if Marie had died there and there, statistically it would have been considered a 'good death' as she had died 'at home'. In policy terms it would be considered a success as it shows that people die in the place 'they want'. Marie's experience shows how dying can 'just' happen. Here we see the problematic nature of just focusing on place when considering death in older age. Dying is messy. On the one hand, people could die in their sleep, peacefully in their own bed, but on the other hand people could die from a major health event, or a falling accident. It is important to acknowledge the range of ways 'dying at home' can occur.

One of my participants, June, a 93-year-old former librarian, died during the course of my study. June had been very clear about what she did and did not want. She had written everything down: she wanted to die alone and she wanted to die in her current dwelling. June had been experiencing health problems for quite a while. At the time of our meeting she had been diagnosed with bowel cancer which interfered with the way she had envisioned her own death. She had been very determined not to receive any medical interventions but with the particular case of this cancer she had to face the reality of how to cope. She told me, "I have to make some important decisions, I thought I made all the decisions I needed at my age". At the point of her bowel cancer prognosis there was growing disjuncture between her wishes and reality of her end of life. While June had anticipated her death and dying, her expected ending could not be achieved with the bowel cancer prognosis, as she would die in a lot of pain if this was left untreated. It also made it impossible for her to die in her own dwelling. In other words, her lived reality challenged her envisioned future and death. As it became apparent that June could not remain in her own dwelling she had to think about where else she could go. I did not speak to her about this but after June's death I interviewed one of her close friends who told me:

The only thing she asked for was a white uncluttered room, with a view. A familiar English view. That was what she wanted. And she wanted her bed to face the view. That was all she asked. And we found that for her. And within a day of all of this happening there she was looking at quintessential English countryside.

June did not die in her own dwelling, but in a care facility. Her death shows the limitations in understanding 'home' as one particular place whereas 'home' can be so many things in a person's life. For June 'home' at the end of life was the 'quintessential English countryside' and by looking at this she was 'at home' albeit not in her own dwelling. This is crucial in understanding the complexity of ageing and dying. Older people are ageing and dying for the first time and coping with issues as they arise. It is very difficult for people to anticipate what is desirable and what not until they are confronted with particular issues.

Discussion

If the focus is to remain on preferred place of death, it is important to unpack what people mean when they say they 'want to die at home'. Here I have suggested that policy could benefit from a broader understanding of home, informed by the social science research on this topic. Ultimately, a 'one size fits all' approach to understanding the preferred place of death is not helpful as it does not take into account the continued evolution of individual life stories and the dynamic relationship between people, places and

their bodies. Accordingly, considering a home death as the gold standard is problematic, as it does not make room for the actual lived experience of people and their individual preferences. Rather, the notion of 'home' is in constantly in flux and people's relationships with their dwellings are not always positive.

Furthermore, an unquestioned preference for the home as the ideal place of death can obstruct any meaningful discussion and provision for people who do not wish to die 'at home'. At present, 'home' is presented in end of life strategy documents (Public Health England 2014; Department of Health 2012) as a clear 'best place' to die, meaning that those who reject this can be regarded as deviant. The key to future best practice is therefore to ensure there are opportunities for older people to discuss their preferences over time, including acknowledging that their wishes may change according to how they are experiencing their body and dwelling, as the aging process develops. Similarly, the notion that some people do not have any preferences or desires to plan ahead deserves more attention too.

Older people are aging and dying in a myriad of places. While the dominant discourse emphasizes the importance of dying at home, this is problematic for various reasons. Firstly, there is empirical evidence that the home-environment is not always safe and comfortable to be in at the end of life (Penney 2013; Means 2007). Secondly, a large group of older people is not aging and dying within the home-environment. Many older people age in nursing homes and care homes. Additionally, while not the topic of this paper, a growing number of older people are aging in prisons and forensic settings. Furthermore, there is also a growing group of homeless people dealing with end-of-life issues. What this shows is that aging and dying in any place is complex, and this complexity has to be taken into account when practically thinking about the reality of death, irrespective of location. This paper has suggested that the dying at home discourse could be lifted from the physical boundaries of the dwelling and moved to other locales; what does dying 'at home' in hospital; dying 'at home' on the street, or dying 'at home' in prison look like? These are questions that have to be answered as people will die in these places, irrespective of what people might perceive as the ideal. Any place can become someone's home and therefore, potentially, dying in any place could be a home death. However, in some places it is more difficult to create a 'home-like' environment, particularly in a place where you don't want to be.

Older people have a lifetime of experience of homemaking, and therefore may have various and perhaps contradictory understandings of what is 'home', and what not. People's lived experience shapes the way they envision their death and process of dying. Older people can have specific ideas of what they want to happen in life, but their experience of their bodies, relationships and space can develop and evolve in unpredictable ways right up until the moment of death. Hence, the fluidity of and temporality of home-making has to be taken into account when thinking about good policy and practice. By understanding 'home' as a complex multi-layered concept, 'home deaths' potentially could occur in any setting, may it be the dwelling, hospital, nursing home or hospice.

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