

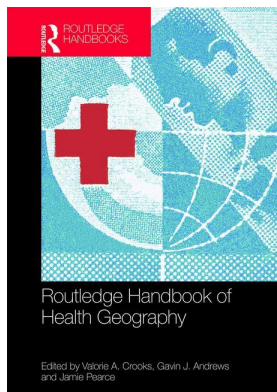
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HOME TRUTHS? A CRITICAL REFLECTION ON AGING, CARE AND THE HOME

Christine Milligan

Where and how we spend the most significant moments of our lives is an issue of importance to all. This can be particularly so where poor, or declining, physical and cognitive health and mobility may limit our ability to make choices.

In the United Kingdom, as well as other high-income countries, disclosures about the adverse impact of institutional care on the lives of both residents and staff from the 1960s onward (e.g., Goffman, 1968; Johnson, Rolph and Smith, 2010; Townsend, 1962), combined with a widespread shift in thinking around who and where care and support for those experiencing physical or mental disability should be provided, resulted in the emergence of policies and practices designed around community-based care. This sought to shift the provision of care and support away from institutional settings to community and domestic environments. Within health and social geography, this shift manifested in a refocus of interest on the (domestic) home as a key site of care and support. Here, the home was viewed not just as a physical structure within which life, death and care are played out, but as a space imbued with multiple meanings linked to identity, safety and security, privacy, power and control, emotion, nurture and historical memory (e.g., Blunt and Dowling, 2006; Chapman and Hockey, 1999; Collier, Phillips and Iedema, 2015; Imrie, 2004; Langstrup, 2013; Milligan, 2000, 2009; Twigg, 2000). Work in this field has played an important role in helping us understand the meaning of home – particularly for physically and mentally ill, older and disabled people and family caregivers – through its critical engagement with the home/care nexus. It has also illustrated how an understanding of the multifaceted and relational nature of home is key to the development of successful policies and practices designed around health, care and the home. By and large, the focus has been on aging in place, community care for those with physical, mental and intellectual disabilities and the home death.

Drawing on debates within health geography and environmental gerontology, this chapter aims to critically examine some of the paradoxes that surround notions of home and care. Engaging with ideas around the public and private, belonging and isolation, identity and alienation, the chapter both explores and challenges prevailing orthodoxies around the meaning of home and its conceptualization as a site of safety and security, power and identity, privacy and control.

The meaning of home

Conceptual thinking around community care and aging in place was built on the premise that the home is the optimum space in which to provide care and support for older and/or disabled people in ways that will

enable them to remain as independent as possible for as long as possible. The home is viewed as a setting that is both familiar and imbued with particular meaning. Implicit within this notion is an assumption that the ongoing and temporal process of inhabiting a familiar place somehow results in the development of a unique sense of attachment that is both supportive and adaptive. Critical to understanding this sense of attachment is the notion of home as haven. To paraphrase Tuan (2004), this represents home as a place of security, familiarity and nurture, where an individual can retreat to a private world away from public scrutiny and where s/he can control decisions about whom to admit or exclude. This ability to control decisions about whom to include or exclude from the home is also viewed as enhancing a person's sense of self and independence. This can be particularly important for those older and/or physically or mentally disabled people who may feel vulnerable negotiating unfamiliar or challenging environments beyond the bounds of their own home, and where the surroundings of the home provide an important buttress to their sense of self (Milligan, Gatrell and Bingley, 2004; Sacco and Nakhaie, 2001). In this way, the home, and attachment to home, is viewed as key to successful aging in place.

From the late 1970s onward, Rowles's (1978, 1993) work on home and its local environs played an important role in revealing how, as people age, the lifeworlds they inhabit contract to become increasingly focused around the home. In large part, this is linked to issues of social and physical access and mobility. As the work of Wiles (2005), Lager (2016) and others has demonstrated, even relatively simple things, including the presence or absence of key design features and services such as even pavements, dropped curbs, toilets, seats and cafes in local settings, or physical changes to once familiar local environments, can severely curtail the geographical reach and wayfinding of people experiencing physical or cognitive limitations. Rowles' (1993) focus on the home, however, led him to suggest that a person's temporal knowledge of the home, combined with his or her physical attachment to it and the routines performed within it, held the potential to facilitate a person's ability to negotiate that space, despite physical, cognitive or sensory loss, without coming to harm. Framing this knowledge and attachment as a *preconscious sense of setting* (p. 66), Rowles argued that it can be employed positively to support an individual's ability to self-manage even as physical or cognitive abilities begin to decline.

The literature on care, home and older people also highlights its importance as a site of historical memory and identity (e.g., Angus et al., 2005; Brickell, 2012; Milligan, 2009). Private possessions and familiar objects within the home can reinforce this sense of self and identity, bestowing personal meaning to the home (Rubinstein, 1989). This anchors people not only within the home, but within a particular locality, as a site of memory and a daily reminder of continuity with past identity and relationships. More broadly, relatively new initiatives such as the development of dementia-friendly communities and attempts to understand what makes an environment dementia-friendly from the perspective of the person living with cognitive decline, are very much underpinned by notions of historical memory and identity (Davis et al., 2009; Mitchell and Burton, 2006). Also of relevance here is the growing focus on the significance of home as the preferred place of death. Williams (2004), for example, maintained that for many people, 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 person requiring care and support, but also for family carers who are faced with the physical and emotional upheaval of care work within the home, potential impending death and the sense of helplessness all this can engender. Collier, Phillips and Iedema (2015) further highlighted the importance of home at end of life as an expression of social and cultural identity, including those symbolic and affective connections manifested through loved ones and meaningful artifacts. Yet as Milligan et al. (2016) point out, facilitating a home death can also create an ambiguity of place, especially for family carers, where the issues they face in caring for a dying older person at home, and the home death itself, can fundamentally reshape the meaning and sense of home in ways that are not necessarily positive. This highlights the need to problematize some of the rather uncritical assumptions about the meaning and sense of home that have underwritten policies and practices designed around notions of aging in place, community care and the home death.

Critically reflecting on the paradox of home

People's experiences of home are both relational – co-produced by the key actors, actions and objects within – and temporally situated, in that the complex socio-spatial relations of home can shift and alter over time. So, while the focus on home as a site of ease, comfort and security may well hold true for some people at some points in their lives, as Blunt and Varley (2004), Brickell (2012) and others have pointed out, such interpretations of home are often eulogized; ignoring or overlooking the ways in which home can, at different times, be a site of stress, loneliness, fear, neglect or confinement. This highlights the paradox of any policy or philosophical approach that places home at the center of care. That is, the idea that home is a place where belonging and isolation, intimacy and violence, desire and fear, power and powerlessness, identity and alienation, and so forth, can all sit on contradistinction to each other.

Health and social geographers have illustrated 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 (Milligan et al., 2016). Any understanding of the impact of home on both the person requiring help and support and family carers' experiences of the home needs to be alert to these complexities. In particular, we need to be alert to the ways in which the requirements of care and support can shift these socio-spatial relations in ways that alter the meaning and sense of home for those concerned. Hence, while it is important to identify how a sense of home might enhance a person's ability to retain a level of independence within the home despite physical or cognitive decline, it is also important to recognize that increasing frailty over time can lead to a breakdown in that preconscious sense of setting as the requirements for care and support increase. This includes 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. These disruptions range from the need for space to perform care work, to the equipment designed to facilitate it (hoists, ramps, commodes, hospital beds, wheelchairs, nebulizers) – all of which can infiltrate and alter that preconscious sense of setting. Such transformations can manifest as either permanent or temporary rearrangements of the home (for example, from the temporary presence of a hospital bed or equipment to the more permanent installation of stairlifts, wheelchair ramps, wet rooms, granny annexes, etc.). The once familiar layout thus becomes unfamiliar, the ability to negotiate known spaces becomes challenging and the preconscious sense of setting breaks down. This can be particularly important when a person's cognitive and sensory abilities may be failing. In such circumstances, the person's sense of home can become increasingly institutionalized as the paraphernalia and requirements of care and support take over.

As Twigg (2000) and others have demonstrated, a further consequence of the complex and shifting social relations of care is often manifest as a declining ability to exclude others (e.g., care providers) from even those most personal and private areas of the home. Twigg's work, for example, was seminal in its illustration of the ways in which the home is divided into a range of public and private spaces. The public represented spaces such as hallways and living rooms – open to those visitors invited into the home but who were excluded from those deeply private and personal areas of the home, such as bedrooms, to which only the closest of friends and family might be given permission to enter. Yet as health deteriorates, and a person's ability to negotiate the home declines, the requirement to grant others, such as carers and care workers, access to those private spaces of the home increases, resulting in a declining ability to exclude and a blurring of the boundary between those areas that had formerly been deemed public and private spaces of the home.

Fundamental to many of the assumptions about the importance of the sense and meaning of home in supporting home-based care and support is the notion that home-based care takes place within the homes of the older or disabled persons themselves – but that, of course, is only a partial picture. For many (often lone-dwelling) frail and disabled people, the need for increased care and support can result in a move from the familial home to a new home-based setting, such as the home of a close family member (often an adult child or sibling) or a supported or extra-care housing environment. Here, the multiple meanings of home,

and those attributes of home viewed as enabling and supportive, can be disrupted for both the recipient of care and the family caregiver (Milligan et al., 2016). Such 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, which can impact both care recipients and family caregivers' own well-being. At the farthest end of the spectrum, the provision of a home death for a spouse or close family member can irrevocably change the nature and physical engagement with the home for those remaining (Milligan et al., 2016). For some, this can represent a shift from *home* to *house* – a space now empty of those personal and emotional relations that underpinned the meaning and sense of home. For others, this may result in a desire to remove from that setting and recreate a new home and a new life – one that is not imbued with an historical memory that has become shadowed by loss.

These shifting and temporal processes of home-based care are illustrative of the juxtaposition between private and public space and the shifting relationships of power, independence and autonomy that can accrue for older and disabled people across a continuum of physical and cognitive abilities.

The home/care dichotomy

While the (re)domestication of care serves a range of political and professional agendas, it is based on an idealized version of home and care; as such, it runs the risk of over-romanticizing notions of care that privilege the home (Rowles, 1993; Exley and Allen, 2007). Not only is there a danger of placing too much emphasis on familiarity and emotional attachment to place as a component of residential preference, but it is important to recognize that not all older people are attached to their home or community in the way that policy might assume. The discourse of aging in place, for example, is underpinned by a number of assumptions: firstly, that older or disabled people necessarily have access to safe and stable housing; secondly, that the home is a place that enables self-expression and identity – a social space where individuals can relax and be at ease; and, thirdly, that the home is a space where privacy can be maintained and where choice and autonomy can be augmented – ultimately, a place where an individual's needs can be best met. It privileges the value of caring relationships without acknowledging the interaction of pre-existing social relationships with the actual work of caring. Hence, it is also based on the assumption that the home is synonymous with loving relationships – in other words, it assumes that caring *about* is the foundation for caring *for*. The home is thus privileged over the institution as the preferred site of care, with the latter often being characterized as a place where the needs both of the institution itself and of group living put a strain on caring ideals.

We should not forget that for some, the home represents a site of fear, physical and mental abuse, neglect and/or violence (Blunt and Varley, 2004; Meth, 2003). Inevitably the private nature of the home – and, by extension, policies designed to facilitate aging in place – is likely to impede the detection of abuse. Indeed, one review of studies looking at elder abuse across a range of (mainly, but not exclusively, Western) countries noted that around one in four vulnerable older people who are dependent on family carers are at risk of psychological abuse, with a further 5–6% subject to physical abuse and neglect (Cooper, Selwood and Livingston, 2008, p. 158). A study by Bonomi et al. (2007) in the United Kingdom also found that a small – but significant – percentage of older women requiring care and support were physically or sexually abused by their own spouses. Abuse is not restricted to family carers, however; as Bonomi et al. further noted, one in six professional carers commit psychological abuse, with one in ten committing physical abuse. For an important minority of older people, then, the promotion of policies designed to support aging in place does not necessarily equate to *good care*.

Idealized assumptions about the home/care relationship can thus mask its inherent tensions. It can bring with it contradictions and strains that are often unacknowledged and that create challenges not only for older people, but also for those providing their care and support. For example, tensions exist between (a) home as habitat and as a site of social and emotional expression and (b) home as a place within which the mechanics of care work, and the regulation attached to its performance (particularly formal care), are enacted. The

home/workplace dichotomy was, perhaps, exemplified by the introduction of legislation in the United Kingdom in 2006 that prohibited smoking in the workplace. Care providers are now in the position of having to request that care recipients refrain from smoking in the private space of their own home during periods in which formal care work is taking place.¹ How enforceable this legislation is within the private space of the home is debatable, but clearly any suggestion that noncompliance could result in service withdrawal will be of significant concern to both family carers and care recipients. It would, however, be exceedingly difficult to apply and monitor such legislation in relation to the performance of family care – particularly co-resident care. Similarly, while formal care work is subject to health and safety regulation, no such regulation applies to the work performed by family carers. So, while aging in place highlights the increasing porosity of the boundaries between home and work in the field of care, it also highlights the inequities in the conditions of formal and family care work within the home.

In addition to the tensions between the home/work relationship, it is also important to critically evaluate how older people, themselves, perceive the relationship between home and the place of care. Many older people assess the benefits of aging in place in an entirely pragmatic way (Milligan, 2009). That is, their key concerns are focused around issues of cost, comfort and convenience and, as such, have little to do with any sense of physical, social or emotional attachment to place. Rather, for an older person's ability to remain at home in a community that he or she is knowledgeable about, and integrated into, local networks of care and support are meaningful because they enable individuals to call on practical assistance from friends and neighbors rather than having to rely on formal care options. It is also worth pointing out that while there is substantial evidence to suggest obligatory relocation can have adverse health consequences (e.g., Ferraro, 1983; Keister, 2006; Pruchno and Rose, 2000), the negative consequences of relocation will not be the same for all older people. Where home represents a site of loneliness, fear and abuse, the experience of relocation may well manifest in improved well-being.

One final dichotomy around home and care focuses around the family and how to balance the right of the older person to age in place versus the cost to the family carer. Although legislation in the United Kingdom now acknowledges the rights of carers, this is not just a legal matter. For example, whose rights and desires should prevail when a person wants to remain at home but the family carer is concerned about risk and danger or feels unable to provide an adequate level of care? These are ethical dilemmas that, in the United Kingdom at least, have yet to be fully tackled by policy-makers; though new models of care, often supported by technology, may go some way toward addressing them.

Where now?

Policy drivers focused around community care, aging in place, the home death, dementia-friendly spaces, et cetera, in most high-income countries are based on assumptions that home is the best place in which to locate care. For some, it is undoubtedly the case that home provides an environment that is supportive as health and mobility declines, but as the discussion above illustrates, this is not the case for all. In this chapter, I have sought to take a more critical lens to examine the nature and meaning of home in relation to declining health and care. As the literature illustrates, home can also be a site of loneliness or fear; the requirements of care may fundamentally shift the nature of home in ways that disrupt people's sense of home and those very facets of home that were seen to provide a supportive environment in the first place. Interestingly, to date, most of the literature focuses on the nature of home as it relates to the home of the care recipient – there is little recognition that as care needs increase, the care recipient may well be cared for in the home of the family carer – and what the implications of that are in terms of home for the carer and the care recipient. There is also little consideration of the changing nature of home for the family after a loss – through bereavement or through a family member's move to residential care – or how these experiences of home and care may vary within and across cultural settings. With their critical lens on unpacking the multifaceted

and relational nature of the home/care nexus, these are avenues of research that health geographers are well-positioned to pursue.

Note

- 1 Although clearly it would be far better not to smoke at all, the reality is that (at least among current generations) many older people still do – and see little benefit in attempting to stop, at their age.

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