

ARTICLE

# Death, dying and disparity: an ethnography of differently priced residential care homes for older people

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## Abstract

Recent scholarship has highlighted the experiences of, and various challenges faced by, dying persons and the workers tasked with end-of-life care. However, research has not sufficiently considered what symbolic resources – such as beliefs, rituals and vocabularies – are drawn upon by care workers when caring for dying and deceased residents in care homes, together with how this is informed by financial regimes. I address this deficit by drawing upon an extensive ethnographic study, undertaken in southern England (United Kingdom) between 2013 and 2014, at two residential care homes (one low-cost and one high-cost) for older people. Counter to analyses of death and dying that too frequently foreground the extraordinary, rather than the mundane and everyday, I examine the gaping disparities between two differently priced settings. In the low-cost home, residents experience a social and moral death. The *dying* and the *dead* are treated with disregard and indifference. In the high-cost home, caring for the living was extended beyond the biological termination of life. This was influenced not only by the marketing of ‘high-quality’ care, but also by workers and residents who, in their gestures and rituals of honouring, remembering and mourning the dead, made high-quality care possible. My analysis shows, then, how cavernous inequities unfold within the care sector and how, in turn, experiences of death and dying are deeply fragmented by the market. I conclude by arguing that researchers must both take the normative and symbolic culture of care work seriously *and* examine how the availability of this is directly impacted by the costing and funding of care. Doing so, I argue, allows us to work towards establishing a care sector that is equitable both for older people and care workers.

**Keywords:** care; care workers; death; dying; materiality; older people; social care; social theory

## Introduction

Individuals in the United Kingdom (UK) are increasingly experiencing an extended phase at the end of life. Whilst a person’s home dwelling is regularly heralded as the

ideal place for an individual to die (Collier and Broom, 2021), care homes are spaces in which such end-of-life care is commonly provided. There are different types of care home in the UK, including residential homes (where ‘personal care’ (washing, dressing, taking medication, etc.) is provided), nursing homes (which includes providing personal care and assistance from qualified nurses) and care homes with dementia care. In this article, I report upon my ethnography of residential care for older people in two settings in southern England. Residents in care homes are living on the margins (Nicholson *et al.*, 2012) and are often seen as places where older people go to die (Froggatt, 2004). It is for this reason, perhaps, that providing a ‘good death’ for older people in care settings is considered a key aspect of quality care (Ellershaw *et al.*, 2003). In 2014, the UK Government (Department of Health, 2014) announced ‘new priorities’ for end-of-life care, calling for the personalisation of care-giving to people at the end of life, and the promotion of a ‘stronger culture of compassion’ in health and social care settings.

But what does a culture of compassion, and a good death, look like? I begin this article by outlining some of the literature on death, dying and care-giving practices. I describe both the primary contentions of this work and where my research can make a contribution, namely by focusing on the disparity of dying care in two differently priced residential homes. From here, after describing my study design and introducing the research sites, I explore what symbolic resources – such as beliefs, rituals and vocabularies – are drawn on by care workers when caring for dying and deceased residents. I found deep disparities between the two (differently priced) settings. In the low-cost home, residents faced a social and moral death; *the dying* and *the dead* were treated with disregard and indifference. In the high-cost home, caring for the living was extended beyond the biological termination of life. This was influenced not only by companies selling ‘high-quality’ care, but also by workers and residents who, in their gestures and rituals of honouring, remembering and mourning the dead, made high-quality care possible.

My main contribution is an attention to the interplay between the costs of care, work conditions and the quality of (end-of-life) care for older people. I make similar claims to, and draw on ideas from, recent scholarship on the sociology of death and dying, yet extend this by considering what symbolic resources are available to care workers and how this is dictated by financial regimes. By analysing life at two homes at opposite ends of the market, I am able to show the disparities not just in terms of working conditions, but in the quality of care provided to older persons (including following their biological death). I show, then, how current practices of funding and pricing social care have effects that seep beyond the practical and measurable, and into the realm of the symbolic.

## Death, dying and care

Our understanding of death and dying has developed within a range of disciplines, including anthropology, psychology, history and sociology (Walter, 2008). In sociology, canonical (often based in the United States of America) work by Sudnow (1967), Glaser and Strauss (1965) and Blauner (1966) preceded sporadic accounts from scholars including Lofland (1978), Fox (1979) and Marshall (1980). Whilst medical sociologists in the late 20th century attended to death as a matter of

attention (e.g. Prior, 1989; Seale, 1990; Clark, 1993; Lawton, 1998), however, the sociology of death remains a rather modest field: 'general sociology still precedes largely as though no-one dies' (Walter, 2008: 330). Sociology, Borgstrom *et al.* (2019) suggest, has either ignored the end-of-life or overemphasised the dying individual.

Yet, the value of a sociological perspective is obvious. Dying is a social and embodied process (Hockey, 1990); it does not occur in a social vacuum, and people's experiences of it – as a dying person or as a relative/friend of a dying person – are shaped by social contexts (Thompson *et al.*, 2016). Distinct rituals of death, for instance, are cultivated and practised in different societies (Noys, 2005); there is no one way to handle death/dying. Moreover, recent scholarship examines the experience of death among individuals and families, particularly on emotional responses to impending death (Kellehear, 2014), how individuals confront and/or attempt to outlive death (Jacobsen, 2017) and the relational navigation of end-of-life care (Ellis, 2013, 2018; Borgstrom *et al.*, 2019). In her ethnography on the meanings, practices and experiences of end-of-life care, Borgstrom (2014) analysed how end-of-life policies underline patient choice through advance care planning to facilitate a 'good death'. Borgstrom also examines how the people subject to end-of-life policies maintain their relationships and roles by navigating the flow of care and concern in the family. This more 'relational' and everyday perspective – of death that is something negotiated between people (Broom and Kirby, 2013) – sits outside a theoretical focus that centres largely on how death produces 'rupture, crisis, and disruption' (Ellis, 2013: 266).

Other work has focused upon the settings/place where death and dying occur (Cohen and Gott, 2015), with place regularly associated with a good (or bad) death (Collier and Broom, 2021). This has led to concerns about an increasing (institutional) 'sequestration' of the dying from everyday life, expressing a kind of collective denial of the human condition of mortality (Mellor and Shilling, 1993). In its worst cases, it is claimed, this amounts to the 'social death' (Sudnow, 1967) of another person – whose sacredness is devalued whilst they are living – to later reduce the disruptive consequences of actual biological death. Hospitals, hospices and care homes – facilitating the physical separation of ageing or dying persons from the rest of social life – can be understood as a means by which modern societies deal with the threat posed by death (Ariès, 1981; Hockey, 1990). For Lawton (1998: 139), this means sequestering not all dying persons, but *categories* of dying person: 'namely, one who is disintegrating and has a body which is unbounded', a person whose decaying and deteriorating body is set apart from wider society. Sequestering death this way might minimise society's need for collective repair, yet another consequence is that death and dying become an increasing part of the daily reality for care workers in residential and nursing homes (Holloway, 2007; Smith, 2013).

In the UK, a concern with the place of death has resulted in formal end-of-life policies and a more considered attempt to document where people die (Driessen *et al.*, 2021). A dying individual's dwelling is frequently heralded as the most appropriate and desired location to 'die well' (Pollock, 2015). However, this may not always be the case. This also seems to frame hospital care as a site of suspicion and fear, whereas it may be the *best* space for dying persons (MacArtney *et al.*,

2015; Collier and Broom, 2021). Carrying out semi-structured interviews with in-patients at a specialist palliative care unit, MacArtney *et al.* (2016) found that in-patients often saw institutional care as protecting family from social and emotional burdens. Similarly, in an ethnography of two palliative care teams, Driessen *et al.* (2021: 2) push against crude assumptions about geography and identify how palliative care staff engaged in ‘placing work’, with patients and relatives, to ‘make places feel secure and familiar – irrespective of where exactly that may be’.

This literature points to how decisions relating to end-of-life emphasise a person (and, sometimes, their family’s) autonomy. A *person-centred* approach often governs end-of-life policies and is increasingly being used to inform care, including in dementia care homes (Kitwood and Bredin, 1992; Kitwood, 1997). Whilst this approach promotes notions of independence and choice, others claim that this is frequently idealistic (McCormack, 2001) and that its guiding principles do not reflect the lived realities for many older people (Reed *et al.*, 2003). Nonetheless, the notion of person-centred care seems to influence the approaches that are taken in care settings, like hospices, residential homes and nursing homes. Departing from historically critical accounts of such spaces – such as for medicalising death (Illich, 1976) and sequestering dying individuals (Lawton, 1998) – more recent contributions show how these settings can provide a manageable space for dying that espouses a more *holistic* approach, and where there is an emphasis on ‘cheer and life’ (Broom and Cavenagh, 2011: 109). Yet, the likes of Pivodic *et al.* (2018) have shown that, even in countries where person-centred palliative care is well-established (e.g. England, Belgium, The Netherlands), care home residents are still perceived to be dying with physical and emotional distress.

The promotion of person-centred care supplements, and is regularly synonymous with, calls for compassionate care. Compassion is defined as impelling and empowering people ‘to not only acknowledge, but to act’ (Schantz, 2007); it is an under-recognised but essential driver, and alleged indicator of, the quality of care for older people (Van der Cingel, 2011). In their study on palliative intervention in long-term care sites across Canada, Smith-MacDonald *et al.* (2019) examine the practicalities of implementing or operationalising compassionate care, and how care was bound by organisational and systemic issues. Workers, for instance, described ‘time’ as a chief barrier to providing compassionate care in addition to other duties. Health-care aides felt ‘squeezed’, frequently using their free time to provide care. Feeling undervalued and under-appreciated by superiors was also cited as impeding compassionate care. Moreover, literature has shown that compassion is a commonly sought-after trait in care workers themselves; as well as them having ‘a caring spirit’ or ‘a heart for caregiving’, which is innate and cannot be taught (Bell *et al.*, 2010: 225). The compassion required of care workers is frequently expressed in the language of a ‘family model’ of care-giving, which has been critiqued for its exploitative potential by encouraging care workers to work unpaid beyond the formal requirements of their job (Dodson and Zincavage, 2007; Johnson, 2015).

This short overview of the literature has highlighted various issues facing both dying persons and the workers tasked with end-of-life care. However, research has not fully considered what symbolic resources – such as beliefs, rituals, vocabularies – are drawn upon by care workers when caring for dying and deceased

residents in care homes, and how this is informed by financial regimes. Little work has examined how the quality and experience of death and dying for older people in residential care homes is impacted by the interplay between the financial costs of social care and, related to this, the work conditions experienced by care workers. This article attempts to plug that gap. I also take inspiration from Ellis' (2013, 2018) claim that theorising death frequently foregrounds the extraordinary rather than the mundane and everyday. Drawing on ethnographic fieldwork at two residential care homes, in which I explored the everyday routines and rituals of care workers, I show how death is a 'surprisingly quiet affair' (Kellehear, 2014) as well as a 'relational experience' that involves people, objects, spaces and temporalities (Ellis, 2018: 363). Building on ethnographic studies in care homes (e.g. Diamond, 1992; Lee-Treweek, 1997; Rodriguez, 2014; Nakrem, 2015), and by taking mundane matters seriously, I show how death and dying for older people living in care homes is a deeply disparate and inequitable experience.

## Method

Over 800 hours of participant observation were carried out over two years (2013–2014), where I took on the role of care worker for 12 months; first, at low-cost Millstead and, second, at high-cost Shorefield (pseudonyms). Both sites were selected as they were at opposite ends of the local authority's care market. I applied for a job at Millstead and was offered an interview, in which I was asked where I had worked before, told which tasks I would be expected to carry out and asked when I would be available to start working. Shorefield's recruitment process was much more formal compared to Millstead. I sent an application form after noticing that they had a 'carer' vacancy online. Two weeks later, I participated in a group interview. Three days later, I was offered a position and asked to attend training.

Observations were supplemented with 30 interviews with care workers from other residential homes. To recruit for interviews, I initially delivered recruitment posters to all 36 residential homes for older people in the same local authority as Millstead and Shorefield. Just one care worker was recruited this way (though I used this participant as a gatekeeper to recruit seven further participants) and, in response, I changed my approach. I was aware that care workers at Millstead and Shorefield frequently sought additional informal work (e.g. providing personal assistance to older people living in private homes) on classified advertising websites. As such, I posted an advertisement on Gumtree and recruited 22 further participants this way. All interviews were carried out face-to-face or by telephone; the latter was preferred by some due to unsociable/unpredictable working hours. Interviews were audio-recorded and ranged from 40 minutes to 2.5 hours. Most participants were female migrant workers and they were aged 21–63. Using a flexible schedule allowed me to gather data to compare with my observational analyses, and offered care workers a forum to discuss what they felt was significant about their work. Interview questions focused on the ordinary practices, relations and interactions in residential homes, together with a consideration of the moral, emotional and material stresses encountered by care workers. Nonetheless, my observational data formed the core of my analysis, and it is these data that I draw upon here.

The strength of this approach is that it allows me to examine both the everyday practices and the accounts of care workers, including observations of the ‘front-stage’ and ‘backstage’ (Goffman, 1959) of care-giving. One limitation, however, is limiting my focus to only two sites. Nonetheless, employing this approach allowed me to take seriously the complex factors contributing to the provision of good and bad quality care, together with establishing how these factors were routinely navigated by employees and employers. The ethnographic approach has been used with great success in other care home research (e.g. Lee-Treweek, 1997; Rodriguez, 2014).

### **Millstead and Shorefield**

Located in a local authority area in the south of England, Millstead and Shorefield were 1.5 miles apart, but were located in different wards. In the 2010 indices of deprivation, Millstead’s ward was ranked among the top 5 per cent most deprived wards in the UK, whereas Shorefield’s ward was ranked in the bottom 50 per cent. Millstead was a single, private residential home which accommodated 33 residents. It was identified as ‘low-cost’ due to the low fees that were charged to its 24 local authority and nine private-paying residents (the average price paid by the local authority for a funded place was £448 per week). Shorefield was a large-scale corporate home provider. In January 2013, it offered care to 99 residents and the cost of receiving care varied depending on which room a resident occupied and their assessed care needs. The lowest priced fee – including accommodation, meals and activities, but not direct care – was £750 per week. Of the 38 homes in the local authority which formed my initial sample, the cost of care for private payers at Shorefield was the highest, even before taking direct care charges into account. Of the 99 residents at Shorefield, four received funding from the local authority, which paid an average of £540 a week for their care. Shorefield was a purpose-built home which was marketed as a luxury alternative to more traditional care homes, with advertisements often emphasising its activities, entertainment, cuisine and hotel-like facilities.

### **Fieldwork**

Observations were carried out in a ‘covert’ manner. Covert research is frequently understood as a problematic endeavour. Omitting ‘informed consent’ procedures, for instance, is seen by some as evidence that, ethically, the approach cannot be justified (Bulmer, 1982). However, others have problematised this narrative; the complex realities of conducting research, overt and covert, means that promising *true* informed consent is naïve and unrealistic (Bosk, 2001; Calvey, 2008). Moreover, viewing overt research as intrinsically good, and covert research as bad, is an oversimplification detracting from a more nuanced deliberation of ethics (Spicker, 2011). In this study, I selected a covert approach for pragmatic and ethical reasons.

Pragmatically, a covert approach was necessary for gaining access to the less-visible spaces and practices of residential homes, without causing great changes in the behaviours of those whom I observed. My approach was not used to produce an exposé, but, rather, a detailed account of everyday life in two residential homes and the mundane, and less-visible, rituals and routines of care workers. Ethically, a

covert approach was used as I felt that the rights of vulnerable older people were of equal importance to those of care workers, and I did not want my respect for the rights of the latter to avoid studying the possible abuse of the rights of older people. Not researching such settings in this way may mean that possibly abusive practices remain hidden and un(der)reported. In their statement of ethical practice, the British Sociological Association states that the use of covert research can be justified when:

... difficulties arise when research participants change their behaviour because they know they are being studied. Researchers may also face problems when access to spheres of social life is closed to social scientists by powerful or secretive interests ... [It] should be resorted to only where it is impossible to use other methods to obtain essential data. (British Sociological Association, 2017: 5)

I discuss my research design and the covert approach in detail elsewhere (Johnson, 2018, 2023).

### **Ethics**

Ethical approval was granted by the Cardiff University School of Social Sciences Research Ethics Committee. With respect to ensuring ethical conduct during fieldwork, I made notes in a notepad only observable to me and did so in a way that made them illegible to others (*i.e.* I used a personalised shorthand). For interviews, written consent was provided by participants. They were informed that they could withdraw at any stage/refuse to answer certain questions, and were told how the data they provided would be used. When participants became upset, they were told that they could pause or withdraw altogether (none obliged). Typed-up fieldnotes and interview transcripts were stored on an encrypted computer. A further ethical concern was anonymity. I was mindful that publishing my study may lead to participants or residential homes being identified. As such, I used pseudonyms and masked or removed other details that I felt may lead to people/settings being identifiable.

My covert approach raised ethical concerns beyond informed consent, such as reporting the possible abuse of residents. I did observe occasions where my views, beliefs and conduct were at odds with participants. At times, I was deeply troubled by what I observed. Where possible, I took practical measures to address my concerns, including informing the Care Quality Commission of substandard care, reporting illegal underpayment of care workers to HM Revenue and Customs, and discussing poor work conditions and care quality with the care homes' managers. Even when problems or concerns did not emerge, my fieldwork was mentally exhausting and emotionally draining. I became angered by practices that denied both workers and residents their dignity and respect. I was upset by the suffering and/or death of older people. I thought and worried about residents after work, and I felt upset and ashamed when the constraints of the job prevented me from providing the best possible care to them. Although not always pleasant or easy to (self-)examine, thinking through my emotions provided me with a valuable insight into the pressures, tensions and anxieties experienced by care workers.

### **Data analysis**

My iterative approach to data analysis involved a constant dialogue between theory and data. My analysis guided areas of future inquiry, though I remained open to new ideas. Practically, I re-read fieldnotes and interview transcripts, and subsequently generated analytical notes. For observations, analytical notes were made alongside my hand-written notes in a fieldwork diary. In order to distinguish between data and analysis, I used different coloured pens and identified, studied and analysed patterns in the data. This included noting the similarities and differences between observations and interviews with care workers.

### **Dying and death in Millstead and Shorefield**

With death and dying increasingly becoming part of the everyday practices of care workers in residential homes, there is a need to ensure that care homes are not left ritually void, but rather must be symbolically well-resourced if they are to cope with the trauma of death for the dying and the bereaved. But what symbolic resources do those working in residential homes draw on to tackle death's disruptive force? How might the organisation of work prevent or facilitate the carrying out of the ritualistic practices required to mourn the loss of the individual? It is to these questions that I will now turn. In what follows, I identify what symbolic resources were utilised by care workers when caring for dying and deceased residents at Millstead (low-cost) and Shorefield (high-cost).

### **Dying: sacredness, sequestration and symbolic systems**

During fieldwork, I observed, and participated in, the care of several dying residents. When a resident is in the final stages of a terminal illness, it is frequently not possible to transfer them into a wheelchair due to weakness and fatigue. The result, at both Millstead and Shorefield, is that residents often spend the final stages of their lives in their bedrooms and not entering communal areas of the home. Nonetheless, there are marked differences in the routines and rituals surrounding dying in the two homes.

### **Shorefield**

In Shorefield, confinement to a bedroom did not result in the person being left alone. Instead, there was a transformation in the care provided – practically and symbolically – from the moment they were deemed to require end-of-life care. Consider the case of Jill (resident) in the days preceding her death:

In handover, Olivia (lead carer) tells us that Jill must receive one-to-one care for the remainder of her life. We will take it in turns to sit with Jill for two hours each and to note down anything that she says or any change in her condition. As I enter Jill's room, I notice one of her CDs is playing. I take over from Fleur (carer) who tells me that she has massaged Jill's hands and painted her nails. There are fresh flowers on Jill's dressing table and her patio door ... is open. In the two hours that I sit with Jill, I note down when she responds to me, sponge fruit juices into her



mouth and apply lip salve to her lips. When sleeping, Jill's chest rattles, her mouth falls open and she breaths heavily, but she is spoken to as though she is able to engage in conversation. Another resident, Sylvia, comes to visit Jill to say goodbye, as does another carer who is on her break. Each sits and talks to Jill whilst holding her hand.

The care of Jill in the days leading up to her death involved a series of rituals. The massaging of hands and the applying of lip salve, whilst a response to practical concerns about dying residents' chapped hands and lips, functioned to humanise residents. Other practices which moved beyond hygiene maintenance and pain reduction included constant one-to-one care, placing fresh flowers in the bedroom, the use of a diary to mark (social) events in the dying process and holding hands. By symbolically attending to a residents' suffering, such practices reaffirmed Jill's status as *person*.

Moreover, Shorefield staff and residents' families were informed when a resident was dying, and were given regular updates on their condition. A resident's room was never empty; workers would take turns to sit with them (if this was their request) and would only leave when another worker was available. Measures were taken by Shorefield's managers and care workers to ensure that dying residents remained integrated into the collective life of the home, even if they were physically separated in a bedroom. With the dying resident's permission, dying residents would frequently be visited by other residents. Rather than being sequestered or subjected to a 'social death', Shorefield's dying residents remained part of the home's collective life.

Whilst some of the rituals undertaken when a resident was dying took place in all instances of end-of-life care at Shorefield, others were specific to individual residents. As part of the home's formal 'move-in procedure', residents and family members were encouraged to disclose the nature of preferred end-of-life care (e.g. location, visitors, music, last rites/priest visitation). Shorefield's advanced care planning meant that the care of dying residents was personalised, dictated by the individual resident (and their family). This aligns with recent palliative care practices where individuals working in care settings are urged to both establish and follow end-of-life policies that seek to give personalised care to dying persons (Smith-MacDonald *et al.*, 2019). By emphasising choice through advanced care planning as a way to facilitate a 'good death', end-of-life care/policies shape how dying people can be known and positioned as autonomous individuals (Borgstrom, 2014). This also has much in common with the hospice approach to death. Froggatt (1997, 2001) says the ideals of 'hospices as family' and 'holism' shape the ways in which hospice care is delivered by staff to patients and their kin. Much like the care workers at Shorefield, hospice workers are urged to 'deliver care as if caring for their own family' (Froggatt, 1997: 130). In carrying out end-of-life care plans, Shorefield's care workers maintained the resident's identity and their connections to others both inside and outside the home. In so doing, 'the symbolic harmony of *communitas* is emphasised' (Froggatt, 1997: 131).

Many dying residents preferred to stay 'at home' (*i.e.* not at hospital). This was breached in the case of Marilyn, a long-term terminally ill resident who was found struggling to breath, was admitted to hospital, and died two hours later. This left

care workers visibly upset and angry at the circumstances of Marilyn's death. As occurred in Marilyn's case, Shorefield's workers frequently framed hospitalising dying persons as something harmful to those already suffering, and as preventing a 'good death'. They perhaps disagreed with hospitalisation both because it went against the individual's wishes – 'she wanted to die in her home' (Arlene, lead carer) – and because it precluded their carrying out of the symbolic behaviours required by the residential community to uphold the dying person's sacredness – 'she died alone'. The care workers' distress at Marilyn's hospital admission, I argue, can be perceived as indicative of her continued engagement in the collective life of the home.

### **Millstead**

Unlike Shorefield, where workers attempted to reaffirm dying residents' status as persons, a resident's dying at Millfield did not trigger change in care-giving activities. There was no increase in the time spent caring for dying residents, and there was no visible carrying out of symbolic work. Consider the treatment of Judith who, according to the home's care workers, had been 'end-of-life' for two years:

[Judith] is bedbound and remains in her bedroom all day. Judith calls and shouts indiscernible phrases throughout the day but ... the care workers do not engage with her. Aside from being washed, dressed, changed, and fed, Judith's only contact with the rest of the home is through the steady stream of care workers entering her room to pick up or drop off the hoist, charge its batteries on racks in the corner of her room, or drop off and collect wheelchairs. This is all carried out as though Judith is not in the room. The care workers rarely look up to greet her, knock on the door, or appear to notice her hands raise from the bed as they enter.

Judith's room was also used by workers to take a quick break, eat a snack or chat amongst themselves. All these activities took place as though Judith was not present. The care provided to Judith – washing, dressing, changing, feeding – did not depart from the standard routine of personal care-giving. Whilst care workers at Shorefield placed fresh flowers and played music in the rooms of dying residents, Judith's room was used as a storage space for large lifting equipment and spare wheelchairs. Care workers' disregard for Judith's private space, and her presence in it, mimicked the treatment of other, healthier residents too – with some residents' bedrooms used for hot water and as a communal toilet.

In contrast to Shorefield's care workers, who carried out extra time-consuming symbolic work for dying residents, Millstead's care workers did not distinguish between end-of-life care and regular care-giving activities. In my dual role as a researcher and a care worker, I did not once come across any formal palliative/end-of-life protocols. Individual preferences, for instance, were not accounted for (such as where to die and under what conditions, *e.g.* visitors, furnishings). This lack of ritual work suggests that Millstead's residents were persons who, on moving into the home, had already died a social death, and who approached their biological deaths with limited expectations. Here, residents had already been 'sequestered' (Hockey, 1990; Lawton, 1998). In my year at Millstead, I rarely saw a resident leave the building, outings were not organised and several residents were not visited

by family members/friends. However, practices *within* Millstead acted to further sequester dying residents away from others, such as confining them to bedrooms (Froggatt, 2001). Millstead's framing of residents as 'non-persons' allowed the home's management, and several care workers, to view dying residents as inefficiencies disrupting the usual pattern of work in the home. When Millstead's residents asked for assistance outside the home's set routine, several care workers either refused to help or made clear to those residents that they were a burden. This meant that it was often when residents were at their most vulnerable – such as when they were dying – that they bore the brunt of ill-treatment and neglect:

Erica (lead carer) is in Alfred's (resident) bedroom and has removed his bedclothes by the time I arrive to assist her. Alfred is lying naked and uncovered on his plastic-coated mattress as Erica dunks a flannel in a washing up bowl full of luke-warm soapy water and rubs it across his body. His curtains are open, and you can see out into the garden. The room is rather cold. Erica does not talk to Alfred as I help her to dry his body (with a small hand towel) and dress him. Erica enters Alfred's *ensuite* to empty the bowl of soapy water ... Alfred says 'I want to die'. Erica walks back into the room towards Alfred and, looking into his eyes for the first time, says 'go on then please'.

Remarks like this were not common at Millstead, but I did observe an undercurrent of irritation and disrespect pervading care workers' relationships with residents. A typical trigger for expressions of resentment was residents' call bells. The limited time available to carry out tasks meant that when a resident's needs required a change in the schedule, the care workers became more strained. It appeared that one consequence of this was several care workers saw the more intimate and unpredictable demands of end-of-life care as beyond their duties. As such, when a resident was dying, senior care workers would often summon the local general practitioner (GP) whom they would encourage to admit the dying resident to hospital. Whilst this might be perceived as indicative of staff members' lack of training in providing palliative care, it also seemed to be informed by the prioritisation of direct/physical care and the lessening of the more intimate and unpredictable demands of end-of-life care. On one occasion, the workers had 'had enough of cancelling Dulcie's [dying resident] bell' (Adelina) and called a GP to hasten her hospital admission. Once this is communicated during handover, Mahesh (worker) said 'that makes it [the shift] easier for me'.

This practice of encouraging the hospitalisation of residents stands in contrast to the distress observed among Shorefield's care workers when a dying resident was admitted to hospital. Millstead's care workers did not have the time required to meet both residents' physical and emotional needs. Meeting the former was often prioritised over the latter, and hospitalisation solved the problem for (over-worked) staff. Only two of 12 residents who died at Millstead during fieldwork passed at the home. Symbolic work concerning dying was a casualty of work overload. Rituals take time and, given the lack of time available for care workers to carry out the symbolic work required to deal with death appropriately, alternative measures were taken to eliminate death's visibility and disruptive force through sequestration as the 'final stage in the process of death's reversal' (Ariès, 1981: 583). It was

also in workers' interest (workload), and in the proprietor's financial interest, to admit dying residents to hospital (as they can still charge for their care). But what happened when residents *did* die in Millstead and Shorefield?

### Caring for the deceased

Carrying out personal care of deceased individuals is customary in all residential homes. The resident's body must be washed and dressed in preparation for transfer to a mortuary or funeral home. This is to prevent the leakage of bodily fluids in line with infection control procedures. Yet, how these personal care tasks were undertaken was distinct in Millstead and Shorefield. Most notably, activities (rituals) that went beyond the physical preservation of the deceased's body were carried out at Shorefield, but not Millstead.

### Shorefield

When a resident died at Shorefield, care workers would usually be made aware of the death before a shift. Handover would begin with an announcement that a resident had died and, if their body had not been removed yet, care workers could pay visits to them. Consider what happened following the death of Norah (resident):

Though [Norah's] death was expected, the care workers appear shocked and upset. Karina asks 'who cared for her?' and Sara replies 'It was Sue and I. She looks nice and peaceful'. The carers who have just started their shift thank Sara and ask if she is okay. Norah's body is still in her bedroom ... several care workers and residents visit Norah's body to 'say goodbye'. Norah is lying on her back in bed. A single white sheet covers her. It is folded down beneath her arms and is tucked under the mattress. Her hands have been placed on top of one another and beneath them sits a small bunch of fresh lavender which is tied with a ribbon. Though her mouth has fallen open, her eyes are closed and her hair has been brushed ... The room is silent. I have entered Norah's bedroom with Hannah, another carer. She approaches Norah and kisses her forehead before stroking her hand. She sits on a chair alongside Norah's bed and remains silent with her head bowed for several minutes.

The manner in which care of the deceased was undertaken at Shorefield went beyond the practical or hygienic requirements. Workers ask who was present, and cared for Norah, after her death. Norah was washed and dressed, and her hair was brushed, her eyes were closed, and lavender was placed in her hands. Last respects were paid by workers, family and other residents. Hannah's kissing, stroking and head-bowing were respect-giving rituals repeated by other care workers visiting Norah. As shown in Adams' (1992) research, symbolic death rituals preserved the dignity of the deceased individual in the eyes of the bereaved. Rather than an empty vessel to be disposed of, Norah's body was treated with a kind of sacredness. Such rituals, and moral norms, were transmitted informally between care workers. Personal care can include '[giving] them a wash, [changing] their pad and [putting] their best clothes on' in order to 'make them look nice for their family' (Olivia, lead carer). It can also extend to clearing their bedroom of

empty glasses, tissues, gloves and laundry, opening the window, changing bed-sheets, and finding fresh flowers to place in a resident's hand or on their pillow.

In such death rituals, much emphasis was placed on the appearance and imagined 'comfort' of the deceased resident, with Julie (carer) urging me during one shift to treat a deceased resident 'as though they're still alive'. In a curious inversion of how residents at Millstead were treated, one might say the biological death of residents at Shorefield was considered to *precede* their social death. Personhood was granted even after biological death, and it was in these acts that the person's sacredness continued to be upheld. This was also observed in the activities workers undertook between a resident's biological death and their departure from the home. After Agnes (resident) had died and her body was removed from Shorefield, for instance, residents and members of staff form two lines (a guard of honour) leading to the front door of the home. The lobby fell silent, and, as her body passed, residents and staff bowed their heads. Previous activities were only returned to once the two care workers who assisted the funeral director re-entered the building.

These ritualised practices were undertaken in the same way each time a deceased resident's body was removed from the home (and in a communal location). Since Shorefield's residents were still treated 'as though' they were alive after their biological deaths, it was perhaps in the event of their physical removal from the building that their 'social death' occurred. This occurrence signalled the loss of the deceased individual from the collective life of the home and, as such, it is perhaps unsurprising that it was marked by further symbolic work; work which functioned to convey and reaffirm group solidarity.

### **Millstead**

At Millstead, I was not present for either two resident deaths at the home during fieldwork. As such, I asked several care workers about what 'normally' happened when a resident died at Millstead. Their accounts were similar to that provided by Marlene (senior carer):

Marlene: You come and tell us about it and we ring the GP to come and see them. You've got to wash the body. Make it clean and put the clothes on it. Two of us do that because you've got to roll it and it's really heavy. It's not a nice job.

Me: What about when they come to collect the resident? What do we do?

Marlene: You've got to go and help them lift it on the trolley. Make sure nobody sees ... so close the doors when you take it out.

Me: How do we leave the building?

Marlene: You just go the quickest way. So maybe patio door, maybe by the cleaning trolley ... then [residents] won't see it.

Caring for deceased residents at Millstead, from what I observed, did not appear to extend beyond standard infection control procedures. Care workers would carry out basic personal care on the deceased (washing and dressing) before leaving the resident in their bedroom until the funeral director's arrival. Staff did not visit the deceased resident other than to carry out these tasks. At Millstead, personal care of the dying was a practical, rather than symbolic, undertaking; having already

died a social death, it was only a resident's biological death which needed to be managed. The deceased resident, not treated as sacred prior to death, did not become sacred after death either, indicated by Marlene referring to the deceased's body as 'it'. When a resident's attachment to the collective (both outside and inside the home) has been severed prior to biological death, mourning rituals (as a way to reaffirm the collective) were not required, for any loss to the group has already occurred.

Notably, however, Millstead's care workers placed importance on being discreet when moving the bodies of deceased residents. During interviews, care workers whom I spoke to about the practices occurring in their places of work after a resident death described a similar emphasis on removing the bodies of deceased residents 'very discreetly out the door so that nobody knows' (Angela). This exit would often be a side or back entrance, since 'if you went out the front door, you'd have to go past the public lounges' which would result in 'everyone chatting ... and be[ing] like "oh God, there's a dead person"' (Grace). The speedy removal and burial of a body after death may be seen as appropriate, and respectful, in particular settings and cultures. For instance, sharia (Islamic religious law) calls for the quick burial of the body to protect the living from sanitary issues (Balkan, 2015). However, my observations at Millstead were not that this was a practice for ensuring quality care following a resident's biological death or for *protecting* other residents. Instead, I argue that, at Millstead, a resident's death was frequently treated in pragmatic and functional ways. No boundaries were placed around the deceased's body to establish or reaffirm the individual's sacredness. Instead, the emphasis on concealing the deceased's body from other residents was, more likely, due to a cadaver serving as a *reminder* of death. As the residential home lacked the symbolic resources required to deal with death's threat to the group, it became necessary to sequester the bodies of deceased residents.

### **Making sense of death: collective repair and continuation**

So far, I have examined the events leading up to residents' biological deaths and activities immediately following death. But how did care workers navigate the aftermath of a resident's death?

#### **Shorefield**

Since Shorefield's residents often chose to die at the home rather than in hospital, the home's care workers were frequently required to deal with, and make sense of, death. The death of Hettie (resident), for example, was difficult for some workers to manage, repeating several times in the days before her death 'it's too soon', 'she had so much life left in her' and 'she wasn't ready for this'. Her rapid decline was a shock to workers, and her death was observed by Emma, a housekeeper visiting Hettie on her day off to say goodbye, who relayed the story to colleagues:

[Emma explains] as Hettie's daughter, Lizzy, entered the building, Hettie took her last breath. A strong breeze swept through the room 'out of nowhere' and Emma knew that this was 'her going'. Emma waited for a moment before standing from her chair to inform a senior carer of Hettie's death. As Emma entered the corridor,

Hettie's daughter, Lizzy, was walking towards Hettie's bedroom. Emma stopped and looked up at Lizzy and shook her head to signal that Hettie had died. Lizzy approached Emma and hugged her. As Emma relays the story of Hettie's death to us, she and the other care workers speculate that Hettie 'must have not wanted her daughter to see her go' or 'she must have been waiting for Lizzy to get here' and 'sensed that she was here'.

Viewing death as something which is, in part, controlled by the dying individual was common at Shorefield, and care workers used sentimental and imaginative stories to integrate a resident's death into their personal life narrative. Care workers would often remark that a resident 'was holding on to say goodbye' to a relative or resident. Likewise, when residents did die, the care workers would often comment that 'he chose for [name] not to see them like that' or 'she wouldn't have wanted to upset [name] on that particular day'. Whilst care workers would regularly remark that residents were 'ready to go' or 'ready to die', this readiness was not framed in terms of an increased burden but, rather, in terms of the resident's prolonged suffering. They would often discuss the 'unfairness' and 'cruelty' of this suffering and disclose they hoped for its conclusion. Death, as the only solution to suffering, was presented by the care workers as both a welcome relief and a dreaded fate.

Care workers' descriptions of resident deaths at Shorefield were full of symbolism. Notebooks kept in a dying residents' bedrooms, containing workers' musings about a resident's mood or thoughts, would often be passed on to the deceased resident's family. Residents were also involved in collective efforts to mourn the individual, including placing a memorial card and photograph of the resident in the communal café. This ritual was a method for mourning the loss of a group member *and* the individual. Likewise, staff and residents would openly discuss the deceased person, commenting upon their character traits and friendships. These stories often took the form of eulogies, honouring and paying tribute to the individual who had died but, also, presenting the deceased's life as a journey at its natural end. Drawing upon the linguistic and symbolic resources available to them, residents and care workers at Shorefield were able to talk about and deal with death in a meaningful way and to come together as a group.

This was also observed when care workers were informed of, and invited to, a resident's funeral by family members. Residents' funerals, if held locally, were always attended by at least one care worker, and attendance was often organised by the care workers themselves. On other occasions, several members of staff would attend a resident's funeral. This was not dictated by management, but was their choice. It was *their* community; they attended funerals out of a sense of duty to residents and each other. Smith-MacDonald *et al.* (2019) describe how workers at long-term care facilities expressed a need for support and care themselves as they worked through their own grief and mourning, having established strong relationships with residents. It seemed, to me, that something similar happened at Shorefield.

### **Millstead**

In contrast to the collective repair work after a death at Shorefield, a resident's death at Millstead caused minimal disruption to care workers' daily routines. It was common for care workers to be unaware of a death until hours after their shift had

started. On one occasion, Tola and Elizabeth (carers) were disgruntled at not being made aware of Eileen's (resident) death prior to their shift, indicating that, whilst resident deaths at Millstead did not have a *collective* impact, they did result in some sense of loss for *individual* care workers. There is a possibility, though, that this displeasure may have related to uncertainty around the size and content of workload. However Tola and Elizabeth's irritations are read, what is clear is that an absence of symbolic resources for care workers meant death was largely ignored. Without the symbolic resources needed to talk about and deal with death appropriately, they were unable to do this. Whilst there was a discursive avoidance of death, particularly in the presence of residents, there were occasions where it was discussed, often taking the form of humour – for instance, when Agata tells a story to fellow care workers of Jack (resident) asking her to 'kill' him, her responding 'ok then', and him saying 'not now, maybe tomorrow?'

Care workers' vocabulary for dealing with death seemed to focus on humour. Scholars have highlighted how health-care workers employ dark humour when facing death and dying (Scott, 2007; Dean and Major, 2008), likely as a coping mechanism in serious situations. However, in my fieldwork, I read such attempts as disrespectful to older persons. Bodies – particularly soiled, deceased or dying bodies – can shock or repulse with ugly sights or smells (Lawton, 1998). Jokes, thus, might constitute a legitimate, if unedifying, way of displacing or repressing feelings of disgust. It is, perhaps, through using humour that care workers at Millstead made death manageable. Yet, one effect was residents' suffering was trivialised, particularly when they called out in pain, pressed call bells more frequently or expressed a fear that they would die soon. Remarks involved labelling residents as 'overdramatic' and 'crazy', with care for such individuals being delayed or withdrawn altogether. Whilst Millstead's care workers made attempts to manage death's force through humour, Brian (manager) responded to resident deaths by focusing on re-occupying deceased residents' bedrooms, even sometimes prior to a dying resident's biological death:

Winston, who appears to be in the final weeks of his life, no longer attends lunch in the dining room and spends most of his time in bed. Brian has been talking to a middle-aged couple in his office ... Brian walks the couple around the home ... He proceeds to enter Winston's bedroom with the couple. I can hear him discussing the 'benefits' of the room: a window which looks out on to the garden and a hand basin. Winston remains in bed and does not appear to have been acknowledged by Brian or the couple.

Brian's attempts to recruit a new resident to occupy Winston's bedroom were mentioned later in the day by Sorin, a newly employed care worker, who claimed 'that man's going to hell, the greedy lying bastard'. For Sorin, Brian's entering a dying resident's bedroom to 'make the sale' constituted sacrilege. Two months following this, however, Sorin suggested that a deceased resident's bedroom – still containing her personal belongings, unwashed sheets and other personal items – be used to house another difficult resident. It seemed to me that the anomic culture of care at Millstead could eventually demoralise even the most conscientious of care workers.



## Discussion

I started my research expecting to find whilst higher-cost care might offer more lavish accommodation, meals and entertainment, there were important aspects of care which could not be 'bought' without cheapening and degrading it. What I found, however, was an alarming gulf in the quality of care between a high-cost and low-cost residential home. This gulf was perhaps at its biggest in the way that care workers treated the dead and dying. Differences in the availability of material, human and moral resources for care workers, as well as differences in how/if residents were integrated into collective life in the homes, meant that the dying and death of residents signified different things for Millstead's and Shorefield's staff. At Millstead, where many residents appeared to have experienced a social death, it was no surprise that the dying and dead were commonly treated with disrespect and triviality. Death did not denote more than the biological termination of life and, thus, was met with practical (and financial) concerns about workload and reoccupying resident bedrooms. No formal, even informal, end-of-life policies were in place, arguably contributing to a lack of compassionate care. For care workers at Shorefield, death wounded the group and prompted rituals of collective repair. Care of the residents, too, extended beyond the biological termination of life. Shorefield is part of a large corporation, which sells 'quality care' because there is a profitable market for it. Shorefield's care workers and residents, nonetheless, were members of a community who, in their gestures and rituals of honouring, remembering and mourning the dead and dying, made 'quality care' possible.

I argue, here, that quality care for dying and deceased residents is rooted in symbolic systems. Care homes must be symbolically well-resourced if they are to cope with the trauma of death. Developing and sustaining a 'well suited' (Goffman, 1956) institutional culture, which allows and encourages care workers to convey regard and respect for individual residents and each other, requires the presence of certain resources. Firstly, quality care requires an attendance to language. For instance, the importance placed on sentimental and imaginative stories with which to make sense of death and dying at Shorefield was tangible, yet absent at Millstead. Secondly, quality care requires acknowledging the value of materiality, objects and space. There was a distinct difference between how bodies were removed from Millstead and Shorefield, and how objects and *things* (music, flowers, windows, memorial cards) were used in Shorefield for upholding the respect of dying residents. I show how, if care work is to be underpinned by dignity, care workers need access to adequate space and material resources to deliver good quality care adequately.

Thirdly, care workers need time to spend undertaking activities. Reducing time spent with residents can lead to poorer health outcomes for residents. Moreover, limited time (normally via short-staffing) can reduce workers' sensitivity to interpersonal communication and their capacity to perform symbolic work to assure residents' dignity when facing death. It was clear at Millstead that the emotional, invisible and less-measurable aspects of care were the first to be relinquished by care workers when time is scarce (Diamond, 1992). This is affected, I contend, by financial regimes, where austere approaches shape the care that is possible (as shown at Millstead).

Fourthly, I show how cynicism and indifference can result from a workplace's shortage of symbolic, temporal and material resources, which make it challenging for care workers to show respect for the individual and enjoy their labour. Despite wider evidence of poor work relationships in care homes (Kemper *et al.*, 2008), I show – through fieldwork at Shorefield – how a sense of collegiality and collective identity *can* be cultivated among care workers. There needs to be balance to avoid financially and emotionally exploitative forms of self-sacrifice among workers (Dodson and Zinavage, 2007; Johnson, 2015, 2023), whilst still encouraging care workers to find dignity and honour in their labour. Finally, whilst the collective identity of those *working* in homes is essential for good care, a sense of community among those *living* there shapes the treatment and experiences of dying and dead residents. Referencing Shorefield, I capture how an individual's integration into communal life can ensure that they experience a 'good death'.

What was clear in my study, and as I attempt to highlight here, is that the presence or absence of these resources is closely tied up with the funding and cost of care. The residential care sector for older people in England is under strain. A shortfall of workers, funding gaps and increasing demand for residential care places – along with increasing privatisation, commodification and market polarisation of care provision – will continue to impact upon the capacity to secure the future quality and equity of care provision. Residential care is a service in crisis, reflected by how death and dying were managed at Millstead. The sharpness of the contrast between the care provided to residents at low-cost Millstead and high-cost Shorefield is, partly, a result of the fact that working and living conditions at Millstead were so poor. Yet, we must be wary of labelling all care homes or care workers either as wholly terrible or as completely perfect (Foner, 1994). Though there was an ethical dimension to the care which was provided at Shorefield, this is not to say that all practices there were ideal or virtuous. The emotional and temporal demands which Shorefield's management placed upon its staff, for instance, were sometimes unreasonable and exploitative. Nonetheless, by analysing death and dying in both homes, I show how cavernous inequities unfold within the care sector. Harris (1990: 28) claimed that the disproportionate concentration of care on people dying of cancer has 'created an underclass of dying [older] people', informed by seemingly distant attitudes to growing older and mortality. My study suggests, though, that this broad classification of 'dying older people' is fragmented by the market.

### Conclusion: implications for research and practice

Moving forward, the situation for older people unable to afford high-cost care continues to look bleak, particularly in a context of austerity, increasing demand for services and a rising complexity of their needs. The picture painted is of a sector in crisis which is failing older people. My study suggests that, relating to Millstead, this is particularly the case when it comes to end-of-life care in residential homes. The practices at Shorefield, though, offer hope. Likely to encounter considerable challenges over the coming decades, social care for older people is at a watershed moment. It is vital we continue to subject care, and care work, to academic and empirical inquiry that focuses upon care-giving practices for older

persons. Such work must take seriously the normative and symbolic culture of work in residential homes – and how the availability of this is directly impacted by the costing and funding of care. The current funding and regulation of residential care is not working to ensure good quality care for *all* older individuals. It is by recognising this, and studying its effects, that we can work towards establishing a care sector which is equitable both for older people and care workers. As Kellehear (2007) reminds us, how a society approaches death, and cares for its dying, is a reflection of its humanity.

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## References

- Adams S (1992) A gendered history of the social management of death and dying in Foleshill, Coventry, during the inter-war years. *The Sociological Review* **40**, 149–168.
- Ariès P (1981) *The Hour of Our Death*. London: Allen Lane.
- Balkan O (2015) Burial and belonging. *Studies in Ethnicity and Nationalism* **15**, 120–134.
- Bell C, Nash J and Thomas L (2010) *Social Care in England: A Brief History*. Plymouth, UK: Skills for Care.
- Blauner R (1966) Death and social structure. *Psychiatry* **29**, 378–394.
- Borgstrom E (2014) *Planning for Death? An Ethnographic Study of Choice and English End-of-life Care* (Doctoral dissertation). University of Cambridge, Cambridge.
- Borgstrom E, Ellis J and Woodthorpe K (2019) ‘We don’t want to go and be idle ducks’: family practices at the end of life. *Sociology* **53**, 1127–1142.
- Bosk CL (2001) Irony, ethnography, and informed consent. In Hoffmaster BC (ed.), *Bioethics in Social Context*. Philadelphia, PA: Temple University Press, pp. 199–220.
- British Sociological Association (2017) *Statement of Ethical Practice for the British Sociological Association*. Available at [https://www.britisoc.co.uk/media/24310/bsa\\_statement\\_of\\_ethical\\_practice.pdf](https://www.britisoc.co.uk/media/24310/bsa_statement_of_ethical_practice.pdf).
- Broom A and Cavenagh J (2011) On the meanings and experiences of living and dying in an Australian hospice. *Health* **15**, 96–111.
- Broom A and Kirby E (2013) The end of life and the family: hospice patients’ views on dying as relational. *Sociology of Health and Illness* **35**, 499–513.
- Bulmer M (1982) The merits and demerits of covert participant observation. In Bulmer M (ed.), *Social Research Ethics*. New York, NY: Holmes and Meier, pp. 217–251.
- Calvey D (2008) The art and politics of covert research: doing situated ethics in the field. *Sociology* **42**, 905–918.
- Clark D (1993) *The Sociology of Death*. Oxford: Blackwell.
- Cohen J and Gott M (2015) Dying in place in old age: public health challenges. In Van den Block L, Alders G, Pereira SM, Onwuteaka-Philipsen B, Pasman R and Deliens L (eds), *Palliative Care for Older People: Public Health Perspective*. Oxford: Oxford Academic, pp. 107–119.
- Collier A and Broom A (2021) Unsettling place(s) at the end of life. *Social Science & Medicine* **288**, 113536.
- Dean RAK and Major JE (2008) From critical care to comfort care: the sustaining value of humour. *Journal of Clinical Nursing* **17**, 1088–1095.
- Department of Health (2014) *New Priorities for Care*. London: Department of Health.
- Diamond T (1992) *Making Gray Gold: Narratives of Nursing Home Care*. Chicago, IL: University of Chicago Press.

- Dodson L and Zinzivage R** (2007) 'It's like a family': caring labor, exploitation, and race in nursing homes. *Gender and Society* **21**, 905–928.
- Driessen A, Borgstrom E and Cohn S** (2021) Placing death and dying: making place at the end of life. *Social Science & Medicine* **291**, 113974.
- Ellershaw J, Neuberger RJ and Ward C** (2003) Care of the dying patient: the last hours or days of life. *BMJ* **326**, 30–34.
- Ellis J** (2013) Thinking beyond rupture: continuity and relationality in everyday illness and dying experience. *Mortality* **18**, 251–269.
- Ellis J** (2018) Family food practices: relationships, materiality and the everyday at the end of life. *Sociology of Health and Illness* **40**, 353–365.
- Foner N** (1994) Nursing home aides: saints or monsters? *The Gerontologist* **34**, 245–250.
- Fox R** (1979) The autopsy: its place in the attitude-learning of second-year medical students. In Fox R (ed.), *Essays in Medical Sociology: Journeys into the Field*. New York, NY: John Wiley & Sons, pp. 51–77.
- Froggatt K** (1997) Rites of passage and the hospice culture. *Mortality* **2**, 123–136.
- Froggatt K** (2001) Life and death in English nursing homes: sequestration or transition? *Ageing & Society* **21**, 319–332.
- Froggatt K** (2004) *Palliative Care in Care Homes for Older People*. London: The National Council for Palliative Care.
- Glaser B and Strauss A** (1965) *Awareness of Dying*. Chicago, IL: Aldine.
- Goffman E** (1956) The nature of deference and demeanor. *American Anthropologist* **58**, 473–502.
- Goffman E** (1959) *The Presentation of Self in Everyday Life*. New York: Doubleday.
- Harris L** (1990) The disadvantaged dying. *Nursing Times* **86**, 26–28.
- Hockey J** (1990) *Experience of Death: An Anthropological Account*. Edinburgh, UK: Edinburgh University Press.
- Holloway M** (2007) *Negotiating Death in Contemporary Health and Social Care*. Bristol, UK: Policy Press.
- Illich I** (1976) *Medical Nemesis*. New York, NY: Pantheon Books.
- Jacobsen MH** (2017) *Postmortal Society: Towards a Sociology of Immortality*. London: Routledge.
- Johnson EK** (2015) The business of care: the moral labour of care workers. *Sociology of Health and Illness* **37**, 112–126.
- Johnson EK** (2018) *The Costs of Care: An Ethnography of Care Work in Two Residential Homes for Older People* (Unpublished PhD thesis). Cardiff University, Cardiff, UK.
- Johnson EK** (2023) The costs of care: an ethnography of care work in residential homes for older people. *Sociology of Health and Illness* **45**, 54–69.
- Kellehear A** (2007) *A Social History of Dying*. Cambridge: Cambridge University Press.
- Kellehear A** (2014) *The Inner Life of the Dying Person*. New York, NY: Columbia University Press.
- Kemper P, Heier B, Barry T, Brannon D, Angelelli J, Vasey J and Anderson-Knott M** (2008) What do direct care workers say would improve their jobs? Differences across settings. *The Gerontologist* **48**, 17–25.
- Kitwood TM** (1997) *Dementia Reconsidered: The Person Comes First*. Buckingham, UK: Open University Press.
- Kitwood T and Bredin K** (1992) Towards a theory of dementia care: personhood and well-being. *Ageing & Society* **12**, 269–287.
- Lawton J** (1998) Contemporary hospice care: the sequestration of the unbounded body and 'dirty dying'. *Sociology of Health and Illness* **20**, 121–143.
- Lee-Treweek G** (1997) Women, resistance and care: an ethnographic study of nursing auxiliary work. *Work, Employment and Society* **11**, 47–63.
- Lofland L** (1978) *The Craft of Dying: The Modern Face of Death*. Beverly Hills, CA: Sage.
- MacArtney JI, Broom A, Kirby E, Good P, Wootton J, Yates PM and Adams J** (2015) On resilience and acceptance in the transition to palliative care at the end of life. *Health* **19**, 263–279.
- MacArtney JI, Broom A, Kirby E, Good P, Wootton J and Adams J** (2016) Locating care at the end of life: burden, vulnerability, and the practical accomplishment of dying. *Sociology of Health and Illness* **38**, 479–492.
- Marshall VW** (1980) *Last Chapters: A Sociology of Ageing and Dying*. Monterey, CA: Brooks/Cole.
- McCormack B** (2001) *Negotiating Partnerships with Older People: A Person-centred Approach*. Aldershot, UK: Ashgate.

- Mellor P and Shilling C** (1993) Modernity, self-identity and the sequestration of death. *Sociology* **27**, 411–431.
- Nakrem S** (2015) Understanding organizational and cultural premises for quality of care in nursing homes: an ethnographic study. *BMC Health Services Research* **15**, 508.
- Nicholson C, Meyer J, Flatley M, Holman C and Lowton K** (2012) Living on the margin: understanding the experience of living and dying with frailty in old age. *Social Science & Medicine* **75**, 1426–1432.
- Noys B** (2005) *The Culture of Death*. Oxford: Berg.
- Pivodic L, Smets T, Van den Noortgate N, Onwuteaka-Philipsen BD, Engels Y, Szczerbińska K, Finne-Soveri H, Froggatt K, Gambassi G, Deliens L and Van den Block L** (2018) Quality of dying and quality of end-of-life care of nursing home residents in six countries: an epidemiological study. *Palliative Medicine* **32**, 1584–1595.
- Pollock K** (2015) Is home always the best and preferred place of death? *BMJ* **351**, h4855.
- Prior L** (1989) *The Social Organisation of Death: Medical Discourse and Social Practices in Belfast*. Cham, Switzerland: Springer.
- Reed J, Cook G, Childs S and Hall A** (2003) *'Getting Old is Not for Cowards': Comfortable, Healthy Ageing*. York, UK: Joseph Rowntree Foundation.
- Rodriguez J** (2014) *Labors of Love: Nursing Homes and the Structures of Care Work*. New York, NY: New York University Press.
- Schantz ML** (2007) Compassion: a concept analysis. *Nursing Forum* **42**, 48–55.
- Scott T** (2007) Expression of humour by emergency personnel involved in sudden deathwork. *Mortality* **12**, 350–364.
- Seale C** (1990) Caring for people who die: the experience of family and friends. *Ageing & Society* **10**, 413–428.
- Smith-MacDonald L, Venturato L, Hunter P, Kaasalainen S, Sussman T, McCleary L, Thompson G, Wickson-Griffiths A and Sinclair S** (2019) Perspectives and experiences of compassion in long-term care facilities within Canada: a qualitative study of patients, family members and health care providers. *BMC Geriatrics* **19**, 128.
- Smith R** (2013) Death and dying in residential care: a matter of concern. *Quality in Ageing and Older Adults* **14**, 205–217.
- Spicker P** (2011) Ethical covert research. *Sociology* **45**, 118–133.
- Sudnow D** (1967) *Passing On: The Social Organization of Dying*. Englewood Cliffs, NJ: Prentice Hall.
- Thompson N, Allan J, Carverhill PA, Cox GR, Davies B, Doka K, Granek L, Harris D, Ho A, Klass D and Small N** (2016) The case for a sociology of dying, death, and bereavement. *Death Studies* **40**, 172–181.
- Van der Cingel M** (2011) Compassion in care: a qualitative study of older people with a chronic disease and nurses. *Nursing Ethics* **18**, 672–685.
- Walter T** (2008) The sociology of death. *Sociology Compass* **2**, 317–336.