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Performing care: emotion work and 'dignity work' – a joint autoethnography of caring for our mum at the end of life

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Abstract In this paper we, twin sisters, present a joint autoethnographic account of providing end of life care for our mum who had terminal cancer. Using the theoretical framing of performance from Goffman's theory of Dramaturgy, we present the findings from a joint autoethnography, focusing on two key themes: performing emotion work and performing what we conceptualise as 'dignity work'. This paper's contributions are twofold. First, conceptually, this paper offers an important contribution to literature concerned with the sociology of illness, by critically engaging with Goffman's notion of frontstage and backstage performance, applied to the context of home care provided by family carers. The second contribution of this paper is methodological; we promote the under-utilised approach of a joint autoethnography and argue for its usefulness in the context of end of life care. We contend that the process of writing this paper was emotionally challenging, yet arriving at the final paper, which serves as a legacy of our mum, was cathartic. We argue for the usefulness of written diaries as a backstage arena through which other informal carers can think through, and come to terms with, experiences of death and dying.

Keywords: emotion work, end of life, dignity work, joint autoethnography, performance

Prologue

In July 2019, our mum was told she had just 6 weeks left to live, following a 5-year battle with secondary bowel cancer which had spread to her lungs and liver (with an initial prognosis in 2014 of 2 weeks to 2 months). This was our mum's third battle with cancer, having had breast cancer in 2015 and bowel cancer in 2016. Mum rang both of us separately on the evening of 16 July 2019 to tell us the prognosis, and the next morning we, Samantha and Catherine, twin sisters and authors of this paper, left our homes and partners in the North West of England to care for our mum, in what ended up being the final 8 weeks of her life. In this paper, we present a joint autoethnographic account of providing end of life care for our mum, Barbara, in her own home. Our mum passed away on 11 September 2019, aged 66. She had been a carer in a number of contexts (home care, residential care, nursing home) for more than 30 years, and through this role she had acquired a very clear idea about where and how she

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wanted to die; that was: in her own home, in her comfortable bed, surrounded by her daughters. We were determined to honour her wishes.

Introduction

We wrote this paper because we want to encourage other informal carers to bring to the fore candid accounts of the *lived experiences* of being a carer for a family member at home. This is important because research in the UK has suggested that, alongside the rewards and pride of caring for a loved one, many carers suffer considerable stress during long periods of caring for someone (Hospice UK 2019). Furthermore, it is important to find out more about the practices and experiences of end of life care by family members in private homes, particularly in the area of cancer care, owing to the high incidence and mortality rates of the disease, in order to ensure the provision of adequate support services.

Family carers are increasingly important in end of life care, since home is increasingly the preferred location for dying, while in-patient hospital care is viewed with suspicion and fear (MacArtney *et al*. 2016). In 2016 in England 46.9 per cent of people died in hospital, 21.8 per cent in care homes, 23.5 per cent at home and 5.7 per cent in hospices (Public Health England 2018). The trend over recent years has been a reducing proportion of deaths in hospital, and an increasing proportion of people dying in their own homes. This said, an individual's home is often hidden from society, and informal care is notoriously under-recognised as a result (Wibberley 2013).

Research suggests that there are rewards, such as feelings of pride, that come with caring for a loved one. However, serious diseases, such as cancer, carry with them considerable psychological and social consequences for family carers (Thomas *et al*. 2002). Indeed, Hospice UK (2019) note that many family carers suffer considerable stress and isolation during long periods of caring for someone. Caring can be identity defining in the way that it changes the life of the person who is caring. This has been documented in the work of Holditch-Davis *et al*. (2011), who discuss the carers' attainment of a maternal role, characterised by mothering, care and tenderness. While Holditch-Davis *et al*. (2011) discuss the attainment of this maternal role in relation to caring for infants, in this paper we discuss the reverse of this. That is how we, as two 29-year-old women, cared for our own mother at the end of her life; through doing so, the power dynamics we had grown up with, of being cared for by our mum, shifted.

This paper focuses on our performances of 'emotion work' and 'dignity work'; terms we will now unpack. Emotion work, according to Hochschild (1979), refers to how emotions are intentionally managed by an individual who induces or inhibits feelings so they are appropriate to a given situation, or to influence others in a desirable way. The related term 'emotional labour' was coined by Hochschild (1983:7) to mean 'the management of feeling to create a publicly observable facial and bodily display'. Importantly, Hochschild (1983) highlights a distinction between emotional labour and emotion work; the former is undertaken by workers in paid employment, whereas the latter refers to unpaid work. Within the professional caring context, emotional labour refers to the emotional effort made by carers to manage their own feelings (Carr and Biggs 2018). Emotion work on the other hand may not be acknowledged as undertaken by 'skilled' workers (Bolton 2004). Emotion work can be undertaken in family and personal life, including informal caring (see Herron *et al*. 2019, Thomas *et al*. 2002).

Emotion work involves attempts to alter the 'degree or quality' of one's feelings through cognitive, bodily and expressive techniques such as shifting one's thoughts, bodily responses such as breathing, and expressive gestures; for instance, laughing or frowning (Hochschild

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2003:95). In the care-giving literature, the concept of emotion work is praised for highlighting the often-neglected emotional dimension of caring, which involves the emotion-charged interactions between the carer and patient and the management of their emotions (Watt 2017). Herron *et al*. (2019:470) maintain that part of emotion work is a family carers' belief that they are responding 'the right way' to their relative, thereby resisting normative emotions. We utilise the concept of emotion work within our paper, paying attention to the effort we exerted in the management of our own emotions when caring for our mum at the end of life.

The term 'dirty work' refers to work that has 'physical, social or moral taint' (Ashforth and Kreiner 1999:414). Ashforth and Kreiner (1999) discuss the challenges of constructing a positive identity for those undertaking so-called dirty work. Hughes (1984) emphasises that inequality is a central feature of all occupations and distinguishes between honourable and dishonourable work. Honourable work provides workers with a degree of prestige, while undertaking dishonourable work typically involves 'mean or dirty' activities (Hughes 1984: 306; Anderson 2000; Ward and McMurray 2015). Often dirty work is characterised by negativity owing to the engagement of the caring body with another body's bodily dysfunctions and discharges (Hansen 2016), including nakedness and touch (Twigg 2000), and decay (Isaksen 2002).

However, Stacey (2005) found that care workers draw meaning from their willingness and ability to perform dirty and mundane tasks that others avoid, knowing that their efforts improve the lives of clients. As such, Stacey (2005) concludes that taking on dirty work is an important source of dignity for workers whose labour is invisible and undervalued by the public. Similarly, Kaiser *et al*. (2019), exploring the experiences of nurses working in palliative care, focus on the respect involved in tasks associated with disgust and repulsion. Taken together, we argue for a reconceptualisation of dirty work as 'dignity work'. In our paper we predominantly use this term in relation to the preservation of the dignity of the patient (our mum). However, reframing dirty work as dignity work is also useful when considering identity literature which suggests that the stigma of dirty work threatens the ability of workers (for instance carers) 'to construct an esteem-enhancing social identity' (see Ashforth and Kreiner 1999:413; Twigg 2000).

The contribution of this paper is twofold. First, conceptually, this paper offers an important contribution to literature concerned with the sociology of illness, by critically engaging with Goffman's (1959) notion of frontstage and backstage performance in the context of home care provided by informal carers. In doing so we highlight that, while in Goffman's (1959) theorisation the backstage is an area that is free from an audience, when caring for someone at the very end of life who is unconscious, the boundaries between frontstage and backstage become increasingly blurred, as the question of what constitutes an 'audience' arises. Furthermore, when caring for someone at end of life, there is a feeling that one needs to be 'on duty' at all times. Thus, backstage opportunities are limited, meaning that it is difficult to find places to 'drop your front' (Goffman 1959). Consequently, the performance of emotion work can be continuous and, as such, emotionally draining. We thus argue that written reflective diaries – which we kept ourselves throughout the process of caring for our mum – are a useful backstage arena in which family carers can write about lived experiences and to release emotions. Second, methodologically, we promote the under-utilised approach of a joint autoethnography, and argue for its usefulness in the context of end of life care. Through this novel methodological approach, our paper goes some way towards redressing the under-recognition of what informal home care involves in an end of life cancer context.

This paper proceeds as follow. First, we offer a brief note on our positionalities before introducing the theoretical framework of performance, drawing on Goffman (1959). We then offer an overview of the methodology and method we adopted, introducing our joint autoethnographic approach. Subsequently, we present the findings from our autoethnographic accounts focusing on two key thematic areas: performing emotion work, and performing dignity work.

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Positionality: a brief note

Both authors, Samantha and Catherine, have previously worked in a caring capacity in residential and nursing homes, respectively, in their teenage years. In 2015-2016, Samantha undertook a postdoctoral research fellow role where she provided hands-on personal and companionship care to people with dementia living in their own homes. Prior to her current post, Catherine was a lecturer (2016-2019) at Edge Hill University, lecturing on the Health and Social Wellbeing degree programme. Despite some subject knowledge and experience of caring, neither Samantha nor Catherine have previously undertaken end of life care. Nonetheless, this positionality and experience of caring provided us with some knowledge and hands-on experience of how to care for someone with decreased mobility.

Performance: our theoretical framing

Performance, for Goffman (1959), is characterised by a series of dramaturgical metaphors, including the world as stage; stage management; front and back regions; guises; and stage props. Goffman (1959) considers the ways in which individuals, in ordinary work situations, present themselves and their activity to others. He is interested in the ways in which the individual projects a version of themselves in order to communicate a certain impression to others, to provoke a desired response. This strategic impression management and primed improvisation in everyday life leads individuals to sometimes act 'in a thoroughly calculating manner' (Goffman 1959:17). Goffman (1959) presents two regions: frontstage and backstage, which complexifies the notion of performance. For Goffman (1959:109;114), 'front region' describes the place in which the performance is delivered, and 'backstage' describes where the performer drops his/her front and offers a more authentic act. The back region is not typically accessible to audience members.

Other comparable papers have found use in this theoretical framing. For instance, Cain (2012) explored identities and presentations of self in the front and back regions of hospice care. Cain (2012) found that frontstage behaviours emphasise compassion, whereas backstage behaviours include dark humour, strategising and detachment. This work was illuminating for challenging assumptions that frontstage actions are only performances and back regions are more authentic, by showing how workers integrate the two into a professional sense of self. In this paper, we critically engage with Goffman's (1959) notion of performance in the context of end of life home care provided by family members. Indeed, we argue that caring in the space of the home complicates Goffman's (1959) simplistic frontstage and backstage binary, owing to the desire to be constantly present for the person you are caring for. Consequently, we argue that it was in written diaries we kept while caring for our mum at the end of life, which we discuss more in the methodology section to follow, that we found a 'backstage' in which we could express authentic emotions.

Methodology and methods

Joint autoethnography

This paper uses the methodology of autoethnography, and specifically a joint autoethnography. Joint autoethnography, sometimes termed collaborative autoethnography, is a 'multivocal approach' (Lapadat 2017:589) in which two or more researchers work together to share personal encounters and interpret the pooled autoethnographic data. As self-reflexive inquiry, autoethnography can be used to recall, retell and reveal bodily embodiment (Allbon 2012).

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The process of autoethnography combines characteristics of ethnography and autobiography that allows individuals to explore cultural understanding through self-observation, which results in individual narratives (Chang 2008). As a methodology, autoethnography enables us to 'open up to the possibility of seeing more of what we might ignore in both ourselves and others, asking why it is ignored, and what we might need to do about it' (Dauphinee 2010:818).

Many autoethnographies are narratives of loss, which are told in a bid to make sense of existential crisis. For instance, Hoppes (2005) explored the meanings and purposes of caring for a family member, through undertaking an autoethnography. While many autoethnographies of care are framed as meaningful and rewarding, Hoppes (2005) candidly tells how caring for this father was characterised not only by love, but also resentment, frustration and anger. He told how he and his father clashed over boundary issues and how 'old ghosts' haunted them as they negotiated a care-giving relationship (Hoppes 2005:263). Moreover, Fox (2010) provides an autoethnography of communication-based interactions she had with her father after he was diagnosed with Alzheimer's disease. Fox (2010) contends that the paper provides a narrative blueprint for how other caregivers may respond to senility.

Much less often seen in the literature are joint ethnographies. For an exception, we refer the reader to Nowakowski and Sumerau's (2019) collaborative autoethnography on the experience of health and illness transformations in the life course. Nonetheless, it is Nowakowski's experience of receiving a conclusive diagnosis of cystic fibrosis after years of misdiagnosis that is drawn on, in order to outline ways in which changes in diagnosis facilitate shifts in illness management, the nature of health and illness and the experience of the self in relation to health and medicine.

Through this joint autoethnography, we offer a thick description (Geertz 1973) of the lived experiences of caring for our mum at the end of life. Like other types of qualitative research, the findings in this paper are not generalisable, nor are they intended to be (Wright 2016). Following Ellis (2004:124), validity/trustworthiness are determined by 'what happens to readers . . . it evokes in readers a feeling that the experience described is lifelike, believable and possible'. Autoethnography, and we argue joint autoethnography, can be seen as transformative in the way that it 'changes time, requires vulnerability, fosters empathy, embodies creativity and innovation, eliminates boundaries, honours subjectivity, and provides therapeutic benefits' (Custer 2014:11).

We are drawn to the notion of reflexivity as a means of representing and reflecting on our role as carers for our mum. Doshi (2014) also exercises reflexivity in an autoethnographic account of caring for her mother with terminal cancer. We argue that joint autoethnography is a valid methodology through which to achieve such reflexivity. We therefore extend Hughes *et al.*'s (2012:209) call for researchers to pursue a 'deeper understanding of and widened respect for autoethnography's capacity as an empirical endeavour', to include joint autoethnography. Allen-Collinson and Hockey (2008:209) note that autoethnography can be considered 'self-indulgent, akin to "navel-gazing"'. Arguably, joint autoethnography can help to overcome this, owing to its shift from individual to collective agency (see Lapadat 2017). What is more, we argue that the experience of caring documented in this paper has relevance beyond ourselves, to other family carers.

Diary keeping

Over a period of 8 weeks (16 July 2019 to 11 September 2019) we recorded in individual personal diaries, observations, thoughts, feelings and interactions of our everyday experiences (Dewalt and Dewalt 2002) of caring for our mum at the end of life. In our diaries, we were concerned with the ordinary, banal everydayness of events and interactions, paying attention to

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taken-for-granted practices when caring for our mum. Travers (2011) promotes the usefulness of diaries for creating a narrative of events, thoughts, hopes and emotions, while Crang (2003:501) positions diaries as useful for eliciting the 'felt, touched and embodied constitution of knowledge'. Our diaries contained highly subjective accounts that we reflected upon, individually and together, periodically.

The diaries were handwritten; we chose to handwrite rather than type diary entries as we associate typing with academic writing. Therefore, we feared that when using a computer we would deliberate about our notes too much, allowing for a process of immediate editing, as opposed to writing how we felt at that moment. We completed diary entries daily, often when our mum was asleep, to ensure that we could recall events vividly. We did not consult each other about the diary format, allowing ourselves freedom as to how we wished to document our experiences, but we found that we both took a similar approach to our diaries, often writing several pages per entry. We found the process of writing reflexively about the experiences of caring for our dying mum emotionally challenging, but also cathartic.

We encourage other family carers to use diary writing as a tool to think through, and come to terms with, death and dying. Specifically, we argue that writing about care experience in diaries can be a means through which family carers can express their backstage emotions, and this can be liberating and therapeutic.

Ethical considerations

Autoethnography has a unique ethical position (Tolich 2010). First, it exposes the researcher's inner feelings and thoughts (Mendez 2013). Autoethnographic writing can lead to the 'vulnerability of revealing yourself' to the judgment of a wider audience (Ellis and Bochner 2000:738). Lapadat (2017) applauds one of the strengths of a joint autoethnographic account as a shift to a shared vulnerability. Tolich (2010:1605) offers the following advice for researchers planning to write about a stigmatised experience: 'they should imagine dressing up in sandwich boards and walking around the university proclaiming their stigma'. Certainly, we are in a place emotionally where we feel comfortable communicating our story with friends, colleagues and the wider public. Importantly, while we do not dispute the vulnerability involved in telling this story, we argue that our joint candid account may provide a means through which other family carers can overcome, what Hospice UK (2019) refer to as, feelings of isolation. Furthermore, Tolich (2010:1605) suggests any autoethnography should be treated 'as an inked tattoo', referring to its permanence on both an author's CV and Internet search engines. For us though, this is an inked tattoo we shall wear with pride.

Second, while the focus of this paper is on ourselves, our feelings, and our experiences of caring, we acknowledge that 'the self is porous, leaking to another' (Tolich 2010:1608), and as such our mum is present in this self-narrative, and the content of many of our autoethnographic reflections is on our mum and her body. It is well accepted that autoethnographic ethics diverge from the focus on informed consent in traditional research ethics (Israel and Hay 2006). We did not seek consent from our mum to feature in the story we tell in the paper. The reasons for this are twofold. First, at the time of caring for our mum, initially we kept our diaries as a reflexive way to think through, deal with and manage our own emotions for ourselves, and did not consider it 'data'. Second, while part way through caring for our mum we considered the idea of writing a paper based on our diaries, we did not deem it appropriate to ask our mum for consent to appear in our narratives. Importantly, Tolich (2010) raises the query: do authors of autoethnographies own their family's stories because they author it? We argue that due to our close embodied knowledge of our mum, and our awareness of her commitment to care in her personal and professional life, she would be very happy for this story to be told.

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Data analysis

We adopted a thematic approach to analysing the data. We analysed by hand as we believed this would facilitate greater closeness to the data, considering this 'human as analyst' (Robson 2011:463) stance important due to the autoethnographic and personal nature of our study (whereby 'the Self of the researcher is integrated into the research', Woods 1996:51). In line with Mauthner and Doucet (2003), reflexivity was important at the interpretation stage of the research, and we recalled our first-hand experience of caring for our mum to make sense of our data.

We revisited our diaries approximately 5 weeks following our mum's death, having had some time to step back from the data and the emotion of the moment. After reading through our diaries multiple times, we separated the entries into smaller, significant parts. We labelled each of these smaller parts with a code, and then compared each new segment of data with the previous codes that we identified. This ensured that similar data were labelled with the same code. We dismissed any preconceived data categories in an effort to 'generate as many codes as possible' (Emerson *et al*. 1995:152). We used memos to comment on parts of our diaries which intrigued us, or that we considered particularly important. MacLure (2008:174) speaks of the pleasure derived from manual analysis, particularly 'poring over the data, annotating, describing, linking, bringing theory to bear, recalling what others have written, and seeing things from different angles'. Crucially, this enabled us to ask questions about what themes we identified through the data. Resultantly, we changed and made linkages between some codes, dropped and added others. Following from this, we undertook a process of abstracting, whereby we condensed the codes into deeper conceptual constructs. We continued this until all coded sections were saturated.

Findings: *Performing* care

The two key thematic areas to arise from our analysis were: performing emotion work and performing dignity work. We discuss these themes, respectively, herein.

Performing emotion work

There were a number of instances when caring for our mum at the end of life in which we managed our feelings to try and keep our mum stress and worry free (see also Constanti and Gibbs 2004). On the same date we found out our mum had 6 weeks left to live, Samantha, the first author of this paper, found out she was pregnant. The last 6 weeks of our mum's life was tinged with happiness that Samantha was able to share this news with her, but also sadness that she will never meet the baby. This is reflected in a diary excerpt below:

> Every day seeing my mum fills me with sadness that she will not get to meet the baby. But each and every day I perform excitement with my mum that she got to share this news with me. Being in the early stages of pregnancy I am also feeling very sick and very exhausted, but I tuck away these aspects, since who am I to complain that I feel ill when my mum is passing away before my very eyes? I perform energy and enthusiasm in the hope that this will be infectious, despite feeling far from energetic and enthusiastic. (Samantha's diary, 27 August 2019)

In the backstage space of diary keeping, Samantha highlights her authentic emotions of sadness, sickness and exhaustion, whereas when she is in the frontstage, sitting by our mum's bed with her, she managed the presentation of self (Goffman 1959), performing energy and

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enthusiasm. This relates to literature concerned with professional caring (e.g. Gray 2009) which characterises the portrayal of emotions as a weakness. Samantha, then, just like professional carers in Gray's (2009) research, makes these emotions invisible in the frontstage. Following Brighton *et al*. (2019), the occlusion of emotions is driven by a desire to put patients' needs first; in this instance, the needs of our mum.

Goffman (1959) describes the backstage as an area that is free from an audience. However, when caring for our mum at the end of life, there were occasions when she was physically present but unconscious and, as such, not verbally communicating. Consequently, the boundaries between frontstage and backstage became blurred, and the notion of what constitutes an 'audience' was problematised:

> I sat on the end of mum's bed today and just looked at her as she was resting, with her eyes closed. As I was looking at her, I could feel myself welling up; she looked so frail and helpless. I started to cry but remembered that mum had told us (and I had also read on the Internet) that hearing is one of the last things to go when someone is dying. Remembering this, I very quickly turned my cry into uncontrollable laughter. If mum could hear me, I didn't want her to think I was upset. (Catherine's diary, 15 August 2019)

In the above excerpt, Catherine can be seen to *perform* happiness; she can be seen to juggle emotions (Bolton 2001), suppressing her genuine emotions in order to put her mum first. When caring for our mum in her own home at the end of life, it was hard to find a 'backstage' (Goffman 1959). We restricted our access to places that could be considered to provide 'backstage escape' such as the bathroom or the garden as were fearful of missing the moment our mum passed away. As the large majority of our time was spent in the same room as our mum, this meant that we had to be 'on duty' (Catherine's diary, 16 August 2019) all of the time in the management of our emotions; this continual performance was 'emotionally draining' (Samantha's diary, 21 August 2019). This links to Hochschild's (1983) discussion of the 'managed heart'; that is, managing emotion to create a facial and bodily display appropriate to a given situation. Indeed, it was in our written diaries that we found a 'backstage' space in which we could express authentic emotions.

Another instance of the management of emotions can be seen in Catherine's diary excerpt below:

> Today mum got put on the syringe driver[1]. She was scared before she was put on it, because she didn't know how it would affect her, but from her experience of caring for others, she knew there was a chance she would not communicate once she was on it. I gave her a hug and we had the following exchange:
>
> Mum: I'm crying, I've got tears down my face
> Catherine: There's only one tear mum [laughter]
> Mum: Bloody hell! What do you want, a waterfall! [laughter].
>
> (Catherine's diary 9 September 2019)

In mum's final 3 days, she had palliative care nurses come in to change the syringe driver every 24 hours. Below, Samantha reflects on how emotions were not only performed when mum was alive, but also once she had passed away:

> The nurses came to change mum's syringe driver today. As they removed the syringe driver mum became alert, sat up, and started trying to speak. She looked in pain though, and her eyes were darting around. I was traumatised seeing mum like this but realising that she could likely hear me, I tried to ask the nurses in a calm tone whether there was anything they could give mum to make her more comfortable. The nurses remained quiet. In

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> hindsight, I think they knew that was mum's final attempt to say goodbye. The nurses put the replacement syringe driver in, and all of a sudden mum went silent and motionless. I suspected mum had passed away, but tried to sound strong and keep my emotions in, just in case she was still with us, so as not to make her worry about us. The nurses confirmed that mum had passed away, but even when speaking to mum once she had passed away, I tried to stay strong, as if she was still with us. (Samantha's diary 11 September 2019)

As the above shows, in performing emotional strength (Gray 2009) in front of our mum, by extension, Samantha was also performing in front of the nurses that were present. Furthermore, the above shows that there is no clear demarcation between performing emotion work in life and death.

Performing dignity work

The second key theme we identified in both of our diaries was the, what we have termed, 'dignity work' involved in caring for our mum in her final weeks. As noted in the introduction to this paper, we have chosen purposefully to move away from the more commonly used term 'dirty work', which Twigg (2000:395) summarises as 'dealing with human wastes: shit, pee, vomit, sputum . . . managing dirty and disgust'. In doing so, throughout this section we emphasise our pride in undertaking tasks including these bodily fluids. This is not to say though that pride was our only emotion experienced; indeed, sometimes when undertaking dignity work we had to perform as if the more negative multi-sensory aspects of bodily care had not affected us.

In the below diary excerpt, Samantha reflects on the dignity work involved in some of the hands-on care we provided for our mum:

> Mum has been itching like mad because of jaundice from her liver failure. Amongst a host of other things, we have been putting calamine lotion on mum's skin to sooth the itching. Mum seems to have lost her inhibitions a bit and is happily flaunting all bits of her body. I have seen more of her today than ever. I tried to cover her up, as I know she would not like to be on display. (Samantha's diary, 14 August 2019)

In the above excerpt, Samantha undertakes direct skin-to-skin care work (Twigg 2000). As well as the tactile dimension to this, Samantha reflects how her interactions with our mum transgressed the boundaries of 'normal' social interactions, relating to bodily boundaries (England and Dyck 2011). Samantha here was mindful of our mum's privacy at the micro-scale of the body, and having embodied knowledge of how mum would usually like to present herself, Samantha covered up mum's body in order to preserve her dignity. While being relatively shocked by our mum's bodily display, Samantha did not let this shock transcend, and she calmly and subtly covered our mum up to make her look more presentable.

Other instances of dignity work undertaken in our care work involved bodily fluids such as blood, saliva and urine:

> Mum coughed up a lot of blood today. Because she was unconscious, I had to get the blood out of her mouth, as I was fearful of her choking. This meant using tissues and wipes to get large clots of blood off of mum's tongue and from the back of her mouth, and catching and blood that dripped from her lips. Sometimes I had to stop myself from gagging as I pulled large clots from her mouth. The smell was horrible, distinctive and like no smell I had come across before. Although it isn't a nice job it is all about giving mum the dignity she deserves in her final moments. (Catherine's diary, 7 September 2019)

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As the above diary entry demonstrates, caring at the end of life was for us a highly multi-sensory experience (Wrubel and Folkman 1997), with not only sights that are visually distressing, but also smells which made us feel nauseous. While we found it somewhat traumatising seeing blood coming from our mum's mouth, and Catherine admits that her body's natural reflex was to 'gag', we put on performances of professionalism. Twigg (2000:401) discusses how care workers 'buckle to and suppress any sense of disgust' through internalising the situation and managing their feelings. In the same way, we suppressed our natural bodily reflexes to ensure mum was unaware of the impact of her porous bodily boundaries on us. We prioritised keeping mum as clean and comfortable as possible in order to preserve her dignity.

Dignity work, despite involving what may conventionally be termed 'dirty work', was not something that was always negatively thought about by us, and was in fact something that we undertook with pride. Indeed, in the below excerpt, Samantha highlights how sometimes we longed to do such tasks in order to ensure mum's dignity was maintained:

> Mum hasn't had the energy to get out of bed for five days now, and as such I haven't been able to assist her going to the toilet, or have a shower. I want mum to feel fresh and clean, but she physically does not have the energy to move. I have sprayed her favourite Prada perfume on her wrist and neck twice a day, so at least mum smells loved, fresh and clean.
> (Samantha's diary, 5 September 2019)

In the above excerpt, Samantha highlights that the absence of being able to perform what England and Dyck (2011:206) term 'intimate body work' (such as bathing and toileting), was very poignant in indicating to us a decline in our mum's condition. We longed to do the intimate bodily work of bathing our mum or assisting her to the toilet, because this was indicative to us of a stage in our mum's health where she had the ability to move. Nonetheless, mum's lack of mobility was not going to stop us from performing dignity work, and in order to ensure mum still felt cared for and fresh, we would spray her with perfume. The perfume to us was a way in which we could facilitate our mum to perform cleanliness that masked the decline in her health.

Another occasion in which we performed dignity work was when we came into contact with our mum's bodily fluids immediately after she had passed away. A doctor came to the house following mum's death to confirm the cause of death, and to record the death formally. He informed us that we could change mum into clothes to be taken to the chapel of rest in if we wished, but made us aware that fluids would leak out of mum's body as we changed her:

> We got mum changed into a pink nightie we had bought her off the Internet, that she never had the chance to wear. It was brand new and fresh and we knew she would want to look her best. As we [Samantha and Catherine] lifted mum up and changed her underwear her body leaked as the doctor warned us it would. Although there was an undeniable sense of horror in completing this task, this was overruled by the enormous pride of seeing mum fresh and clean, and untarnished in her new robe, as she would want to be when she left this world. (Catherine's diary, 11th September 2019)

In the above excerpt we can be seen to engage with what Twigg *et al*. (2011:172) term matter 'out of place'; that is, a leaky, messy body. Furthermore, we can be seen to be undertaking 'body work' (England and Dyck 2011, Twigg *et al*. 2011). That is, the direct, hands-on, handling of our mum's body. Furthermore, the above diary entry shows how, just like we performed our emotions following our mum passing away, dignity work was also something that we not only undertook when mum was alive, but also once she had deceased. This is because we wished to dress mum how we thought she would like to be presented (a fresh, clean outfit), but it was also comforting to us as her daughters to see her looking dignified and loved.

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Conclusions

In this paper, we have presented a joint autoethnographic account of providing end of life home care for our mum who had terminal cancer. We used the theoretical framing of performance from Goffman's (1959) theory of Dramaturgy in our discussion of two key themes: performing emotion work, and performing, what we termed, dignity work. We reconceptualised what has been conventionally termed 'dirty work', as 'dignity work', due to preservation of our mum's dignity that we strived for when undertaking these tasks, and the sense of pride that we derived through undertaking work that could be considered 'dirty'.

Through utilising Goffman's (1959) notion of frontstage and backstage regions, we have contributed to literature on the sociology of illness by critically engaging with the use of this theory in the context of end of life care provided by ourselves, family carers, in the space of the home. We have contended that, while in Goffman's theorisation the backstage is an area that is free from an audience, when caring for someone at the end of life who is unconscious, the boundaries between frontstage and backstage can become blurred – as the notion of what constitutes an 'audience' can be problematised. Furthermore, we reflected on how while caring for our mum at end of life we restricted our access to places that could be considered to provide 'backstage escape', such as the bathroom or the garden, as we were fearful of missing the moment our mum passed away. This resulted in a lack of opportunities to 'drop our front' (Goffman 1959), instead being 'on duty' all the time. Consequently, the performance of emotion work was often continuous, which can be emotionally draining. We argue that in the absence of a physical backstage arena where we could release our authentic emotions when caring for our mum, written diaries filled this void. We thus argue for the promotion of diaries as a 'backstage' space in which family carers can convey the emotional, embodied and affective experiences of caring for a friend or relative at the end of life.

Methodologically, this paper has contributed to literature on the sociology of illness, as we have promoted the under-utilised approach of a joint autoethnography, and argued for its usefulness in the context of end of life care. We do not wish to downplay the fact that writing this paper has been difficult emotionally. Indeed, it has brought to the fore a number of, sometimes unpleasant, memories. Nonetheless, bringing this paper into fruition has been cathartic, and the process of writing it has enabled us to think through, and come to terms with, the multi-sensual experiences associated with death and dying. Indeed, reading the small body of autoethnographic literature on caring for a family member at the end of life (e.g. Doshi 2014, Hoppes 2005), while sometimes tear-jerking, provided us with an important reminder that we were not alone. It is our hope that this candid account of caring for our mum at the end of life will serve as a legacy of our mum. Furthermore, we hope our paper 'speaks to' others who are caring for a dying friend or relative, or grieving for a friend or relative, in the same way that Hoppes' (2005) and Doshi's (2014) papers spoke to us.

Dedication

We dedicate this paper to the memory of our wonderful, bright and beautiful mum, Barbara.

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Authors Contributions

Samantha Wilkinson: Conceptualization (equal); Data curation (equal); Formal analysis (equal); Investigation (equal); Methodology (equal); Writing-original draft (equal); Writing-review & editing (equal).
Catherine Wilkinson: Conceptualization (equal); Data curation (equal); Formal analysis (equal); Investigation (equal); Methodology (equal); Writing-original draft (equal); Writing-review & editing (equal).

Note

1 A small infusion pump, used to gradually administer medicines to help manage, in the case of our mum, pain and sickness.

References

Allbon, C. (2012) "Down the rabbit hole" – "curiouser and curiouser": Using autoethnography as a mode of writing to re-call, re-tell and re-veal bodily embodiment as self-reflexive inquiry, *Journal of Organizational Ethnography*, 1, 1, 62–71.

Allen-Collinson, J. and Hockey, J. (2008) Autoethnography as 'valid' methodology?, A study of disrupted identity narratives, *The International Journal of Interdisciplinary Social Sciences*, 3, 6, 209–17.

Anderson, B. (2000) *Doing the Dirty Work?: The Global Politics of Domestic Labour*. London: Zed Books.

Ashforth, B.E. and Kreiner, G.E. (1999) "How can you do it?": Dirty work and the challenge of constructing a positive identity, *Academy of Management Review*, 24, 3, 413–34.

Bolton, S. (2001) Changing faces: nurses as emotional jugglers, *Sociology of Health & Illness*, 23, 1, 85–100.

Bolton, S. (2004) Conceptual confusions: emotion work as skilled work. In Warhurst, I.G. and Keep, E. (eds) *The Skills that Matter*. Hampshire: Palgrave Macmillan, pp 19–37.

Brighton, L.J., Selman, L.E., Bristowe, K., Edwards, B., *et al*. (2019) Emotional labour in palliative and end-of-life care communication: a qualitative study with generalist palliative care providers, *Patient Education and Counseling*, 102, 3, 494–502.

Cain, C.L. (2012) Integrating dark humour and compassion: Identities and presentations of self in the front and back regions of hospice, *Journal of Contemporary Ethnography*, 41, 6, 668–94.

Carr, A. and Biggs, S. (2018) Emotional labour, person-centred care and problem solving in regulating dementia care. In Macdonald, G. and Mears, J. (eds) *Dementia as Social Experience: Valuing Life and Care* (pp. 174–94). Oxon: Routledge.

Chang, E. (2008) *Autoethnography as Method*. Walnut Creek, CA: West Coast Press.

Constanti, P. and Gibbs, P. (2004) Higher education teachers and emotional labour, *International Journal of Educational Management*, 18, 4, 243–9.

Crang, M. (2003) Qualitative methods: touchy, feely, look-see?, *Progress in Human Geography*, 27, 4, 494–504.

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Custer, D. (2014) Autoethnography as a transformative research method, *The Qualitative Report*, 19, 37, 1–13.

Dauphinee, E. (2010) The ethics of autoethnography, *Review of International Studies*, 36, 3, 799–818.

Dewalt, K.M. and Dewalt, B.R. (2002) *Participant Observation: A Guide for Fieldworkers*. New York: AltaMira Press.

Doshi, M.J. (2014) Help(less): an autoethnography about caring for my mother with terminal cancer, *Health Communication*, 29, 8, 840–2.

Ellis, C. and Bochner, A.P. (2000) Autoethnography, personal narrative, reflexivity: researcher as subject. In Denzin, N. and Lincoln, Y. (eds) *Handbook of Qualitative Research*. London: Sage, pp 733–68.

Ellis, C. (2004) *The Ethnographic I: A Methodological Novel about Autoethnography*. Walnut Creek, CA: Altamira Press.

Emerson, R., Fretz, R. and Shaw, L. (1995) *Writing Ethnographic Fieldnotes*. Chicago, IL: The University of Chicago Press.

England, K. and Dyck, I. (2011) Managing the body work of home care, *Sociology of Health & Illness*, 33, 2, 206–19.

Fox, R. (2010) Re-membering Daddy: Autoethnographic reflections of my Father and Alzheimer's Disease, *Text and Performance Quarterly*, 30, 1, 3–20.

Geertz, C. (1973) *The Interpretation of Cultures: Selected Essays*. New York: Basic Books.

Goffman, E. (1959) *The Presentation of Self in Everyday Life*. London: Penguin Books.

Gray, B. (2009) The emotional labour of nursing - defining and managing emotions in nursing work, *Nurse Education Today*, 29, 2, 168–75.

Hansen, A.M. (2016) Rehabilitative bodywork: cleaning up the dirty work of homecare, *Sociology of Health and Illness*, 38, 7, 1092–105.

Herron, R.V., Funk, L.M. and Spencer, D. (2019) Responding the "wrong way": the emotion work of caring for a family member with dementia, *The Gerontologist.*, 59, 5, e470–e478.

Hochschild, A.R. (1979) Emotion work, feeling rules, and social structure, *American Journal of Sociology*, 85, 3, 551–75.

Hochschild, A.R. (1983) *The Managed Heart: Commercialization of Human Feeling*. London: University of California.

Hochschild, A. (2003) *The Commercialization of Intimate Life: Notes from Home and Work*. Berkeley, CA: University of California Press.

Holditch-Davis, D., Miles, M.S., Burchinal, M.R. and Goldman, B.D. (2011) Maternal role attainment with medically fragile infants: part 2. Relationship to the quality of parenting, *Research in Nursing & Health*, 34, 1, 35–48.

Hoppes, S. (2005) Meanings and purposes of caring for a family member: an autoethnography, *American Journal of Occupational Therapy*, 59, 3, 262–72.

Hospice UK (2019) Family and carers [Online]. Available at https://www.hospiceuk.org/what-we-offer/clinical-and-care-support/family-and-carers (Last accessed 6 April 2020).

Hughes, E. (1984) *The Sociological Eye*. New Brunswick, NJ: Transaction.

Hughes, S., Pennington, J.L. and Makris, S. (2012) Translating autoethnography across the AERA standards: toward understanding autoethnographic scholarship as empirical research, *Educational Researcher*, 41, 6, 209–19.

Isaksen, L.W. (2002) Toward a sociology of (gendered) disgust: images of bodily decay and the social organization of care work, *Journal of Family Issues*, 23, 7, 791–811.

Israel, M. and Hay, I. (2006) *Research Ethics for Social Scientists*. London: Sage.

Kaiser, M., Kohlen, H. and Caine, V. (2019) Explorations of disgust: a narrative inquiry into the experiences of nurses working in palliative care, *Nursing Inquiry*, 26, 3, e12290.

Lapadat, J.C. (2017) Ethics in autoethnography and collaborative autoethnography, *Qualitative Inquiry*, 23, 8, 589–603.

MacArtney, J.I., Broom, A., Kirby, E., Good, P., *et al*. (2016) Locating care at end of life: burden, vulnerability, and the practical accomplishment of dying, *Sociology of Health & Illness*, 38, 3, 479–92.

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MacLure, M. (2008) Classification or wonder? Coding as an analytic practice in qualitative research. In Coleman, R. and Ringrose, J. (eds) *Deleuze and Research Methodologies*. Edinburgh: Edinburgh University Press, pp 164–83.

Mauthner, N.S. and Doucet, A. (2003) Reflexive accounts and accounts of reflexivity in qualitative data analysis, *Sociology*, 37, 3, 413–31.

Mendez, M. (2013) Autoethnography as a research method: advantages, limitations and criticisms, *Colombian Applied Linguistics Journal*, 15, 2, 279–87.

Nowakowski, A.C.H. and Sumerau, J.E. (2019) Reframing health and illness: a collaborative autoethnography on the experience of health and illness transformation in the life course, *Sociology of Health and Illness*, 41, 4, 723–39.

Public Health England (2018) Statistical commentary: end of life care profiles [Online]. Available at https://www.gov.uk/government/publications/end-of-life-care-profiles-february-2018-update/statistical-commentary-end-of-life-care-profiles-february-2018-update (Last accessed 6 April 2020).

Robson, C. (2011) *Real World Research*. West Sussex: John Wiley & Sons.

Stacey, C.L. (2005) Finding dignity in dirty work: the constraints and rewards of low-wage home care labour, *Sociology of Health & Illness*, 27, 6, 831–54.

Thomas, C., Morris, S.M. and Harman, J.C. (2002) Companions through cancer: the care given by informal carers in cancer contexts, *Social Science & Medicine*, 54, 4, 529–44.

Tolich, M. (2010) A critique of current practice: ten foundational guidelines for autoethnographers, *Qualitative Health Research*, 20, 12, 1599–610.

Travers, C. (2011) Unveiling a reflective diary methodology for exploring the lived experiences of stress and coping, *Journal of Vocational Behaviour*, 79, 204–16.

Twigg, J. (2000) Carework as a form of bodywork, *Ageing & Society*, 20, 4, 389–411.

Twigg, J., Wolkowitz, C., Cohen, R.L. and Nettleton, S. (2011) Conceptualising body work in health and social care, *Sociology of Health and Illness*, 33, 2, 171–88.

Ward, J. and McMurray, R. (2015) *The Dark Side of Emotional Labour*. Oxon: Routledge.

Watt, L. (2017) "Her life rests on your shoulders": doing worry as emotion work in the care of children with diabetes, *Global Qualitative Nursing Research*, 4. https://doi.org/10.1177/2333393617743638

Wear, D., Aultman, J.M., Varley, J.D. and Zarconi, J. (2006) Making fun of patients: medical students' perceptions and use of derogatory and cynical humor in clinical settings, *Academic Medicine*, 81, 5, 454–62.

Wibberley, G. (2013) The problems of a 'dirty workplace' in domiciliary care, *Health & Place*, 21, 156–62.

Woods, P. (1996) *Researching the Art of Teaching: Ethnography for Educational Use*. London: Routledge.

Wright, R.R. (2016) Comics, kitsch, and class: an autoethnographic exploration of an accidental academic, *International Journal of Qualitative Studies in Education*, 29, 3, 426–44.

Wrubel, J. and Folkman, S. (1997) What informal caregivers actually do: the caregiving skills of partners of men with AIDS, *AIDS Care*, 9, 691–706.

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