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Journal Item

How to cite:

Borgstrom, Erica; Ellis, Julie and Woodthorpe, Kate (2019). “We don't want to go and be idle ducks”: family practices at the end of life. *Sociology* (Early Access).

For guidance on citations see [FAQs](#).

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Version: Accepted Manuscript

Link(s) to article on publisher's website:
<http://dx.doi.org/doi:10.1177/0038038519841828>

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Abstract

At present end of life research, policy and practice typically prioritises the dying individual and considers the family an orbiting static unit. Sociological theorising of dying has reflected this trend, focusing on the macro-level and public rather than private sphere, whilst sociologists engaged in the study of family and relationships overlooking the end of life altogether. In addressing this gap, this paper argues that the end of life is a relational experience in which everyday family practices are embedded and enacted. Drawing on two ethnographic studies, it demonstrates some of the ways in which family is actively ‘done’ at this time, principally in the transference of family practices into institutional settings, and shared decision making. In doing so it makes a case for moving beyond a highly individualised emphasis on the person nearing the end of their life and an accompanying normative conceptualisation of family, towards an understanding that families (in all their diversity) and their continued (un)making are central to the experience.

KEYWORDS: dying; end of life; ethnography; everyday; family; family practice

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“We don’t want to go and be idle ducks”: family practices at the end of life

Introduction

Proposing that ‘death is a social relationship’, Kellehear (2008) has pointed to the social and cultural contexts in which death, dying, and bereavement occur. Yet, clinical criteria utilised to determine death are based upon research that prioritises the individual dying person, their pathophysiology, and the final moments of dying. This, Kellehear suggests, negates the understanding of the *experience* of death and dying, and results in research, knowledge and practice at the end of life that typically adopts ‘*asocial* ideas of personhood that do not reflect the cultural and interpersonal realities at the deathbed’ (Kellehear, 2008:1533, emphasis added). Whilst Kellehear’s argument is focused on ‘brain death’, his point about the need to understand death relationally can be, and needs to be, highlighted and applied more broadly to sociological scholarship, national policy and frontline practice related to the end of life. In this paper we contend that, sociologists engaged in sociologies of families and relationships should be leading the way in making this case. Such a case is needed because to date sociology has typically either ignored the end of life, or (over)emphasised the dying individual, considering family in more implicit or peripheral ways (for instance, in relation to the ‘good’ death). This in turn contributes to psychologised understandings of death-related experiences, consolidating and (re)producing normative ideas about ‘healthy’ and ‘unhealthy’ behaviour and responses (Walter, 1999). Such a preoccupation with examining the individual and their inner psychological worlds (Small and Hockey, 2001) omits the fact that people have relationships when they are dying, and that the end of life (which is more than the moment of death, see below) is one that is negotiated *between* people (Broom and Kirby, 2013). Moreover, while sociologists are not unique in their oversight

of the relational features of the end of life (Woodthorpe and Rumble, 2016), using conceptual tools like family practices and displays of family, sociologists are best positioned to understand the complexities and dynamics of family relationships.

By focusing specifically on empirical examples of the way in which the end of life is negotiated *between* family members, this paper illustrates what relationships, and specifically 'family life', may look like as family members approach the end of their lives. Drawing on the ongoing interest in the relational turn within the social sciences (Smart, 2007), it contributes to a small but growing corpus of sociological and anthropological work that recognises the primacy of relationships within/and dying, death and bereavement (for examples see Ellis, 2018; 2013; Woodthorpe and Rumble, 2016; Borgstrom, 2015; Peel and Harding, 2015; Szmigin and Canning, 2015; Ribbens McCarthy and Prokhovnik, 2014; Broom and Kirby, 2013). This literature has sought to understand dying and death via an exploration of interactions and networks, resisting the reduction of the end of life to a study of partial elements that emphasises the importance of 'individuals' or 'social structure'. The end of life, as with all phases over the life course, is thus not simply a series of individual experiences, choices and responses; it is something that is creatively enacted between people.

Sociological theorising of family practices (see Morgan, 2013; 2011; 1996) is of particular relevance for thinking about dying as a relational experience, and it is the primary analytical lens we utilise in this paper. 'Seeing families as constituted by what they *do*' (Smart 2007: 33, emphasis added) stresses dynamism and fluidity in terms of family composition and form, and seeks to understand how relationships, be they within a family or between family members and others, are variably enacted and (co)produced in everyday life. Such an approach complicates the sociological narrative about

individualisation and the fragmentation of social ties (Beck and Beck-Gernsheim, 2004; Beck, 2000). It does this by demonstrating how people remain embedded in webs of interdependent relationships despite social and demographic changes, such as dispersed living arrangements, that are understood to compromise of *relational* ways of living (Smart, 2007).

In this paper we contend that there is much leverage in applying this conceptualisation of family life in order to understand the end of life. To illustrate how end of life is experienced relationally via everyday family practices, this paper draws on two ethnographic studies conducted in England. It discusses the evolution of the concept of family practice, sociological theorising of the end of life to date, and the methodological underpinnings of each study, before empirically demonstrating and analytically exploring how the end of life is negotiated. The paper concludes that sociologists who specialise in dying and families need to lead the way in making a case for how relationships shape the end of life. The static presentation of relationships and specifically 'family' in sociological end of life research, national policy and frontline practice at present belies the negotiation *between* people that takes place, and this needs much greater recognition at all levels.

Families towards the end of a life

For many sociologists studying families and relationships, the concept of relationality has become an essential theoretical tool (Roseneil and Ketokivi, 2015). It helps to comprehend how people make sense of their lives, biographies and social identities *through* their interactions with significant others (Smart, 2007). Such ways of thinking about relationships within families, and beyond normative familial structures and

makeups, have resulted in a significant shift in how sociologists conceptualise intimacy (Gabb, 2008; Jamieson, 1998), the 'doing' (Morgan, 1996) and the 'display' (Finch, 2007) of family relationships (May and Dawson, 2018).

A foundational part of this conceptual shift has been learning to understand 'family' as something that is actively and creatively produced through practices enacted by individuals in their day-to-day lives (Morgan, 1996). Avoiding reified ideas about the family unit, family *practice* is thus a sociological concept which highlights the agency and diversity inherent in how family is experienced. It foregrounds routine and habit, illuminating how practices are 'organised around the regular deployment of bodies, time and space and material culture' (Morgan, 2004:40). In turn, family practices are 'little fragments of daily life' that are inextricably entangled with the everyday and constitute our experiences of it (Morgan, 1996:189). Consequently, understanding family as 'the active processes of human creation through ordinary interaction' has made a significant contribution to sociological understandings of the everyday, 'enjoying something of a renaissance in contemporary social thought' (Bennett and Silva, 2004:1).

A surge of interest in family practices in the everyday does not extend, however, to thinking about day-to-day family life towards the end of life (Ellis, 2013). Sociological study of the family has neglected to consider death and dying as a relevant matter for analysis, perhaps because the words 'mundane', 'ordinary' and 'everyday' may seem incongruous in this context. However, due to early diagnosis of life-limiting conditions, many terminally ill people and their families (in 'western' societies at least) live with impending death over a variable and increasingly prolonged period of time (Field, 1996). Indeed, policy in England has a working definition of the 'end of life' as the last year of life (Department of Health, 2008), meaning that the 'end of life' does not refer exclusively

to the immediate period before death. Rather, it covers an extended time period where individuals and their families are engaging with the (protracted) *ending* of a life. In this way, the end of life is the 'final and normal *period of living*' (Kellehear, 2014: xii, emphasis added), where 'everyday' living is still taking place and talked about (Miller, 2017). The concept of family practice as inherently processual and dynamic can therefore, as this paper shows, provide a more vivid understanding of the end of life over a period of time.

This is important as, to date, sociological insights into relationships at the end of life have been gleaned from studies that are substantively about something else related to death – for instance informal care-giving or a 'good death' (see Broom *et al.*, 2016; Seale and Cartwright, 1994; Young and Cullen, 1996). Images of family members surrounding the deathbed have become iconic in the history of western death culture as they represent a 'good death' where there are opportunities to say goodbyes and to allow the dying person to put their affairs in order (Strange, 2009). The implication of these deathbed scenes is that family need to ready themselves to be 'of optimal therapeutic value' (Samarel, 1995: 103) and to learn how to 'be there' for the dying person during the final stages of life. This has been further endorsed in the championing of the importance of family presence by the hospice movement, which trains families 'in the arts of accompaniment' (Seale, 1995: 377).

In the existing literature, in popular culture, and in the most influential social movement at the end of life, family is thus conceptualised and represented as the 'accompaniers' of the dying person, rather than something that is being 'done', negotiated or created through relationally situated behaviour and choices. Such emphasis on dying as *an individual with others* has contributed to, and been reflected in, trends in national end

of life policy in England. One of these trends has been the prioritising of an individual dying within the 'familial environment', ideally at home (see Borgstrom, 2016; Visser, 2018).

Where families have specifically been the subject of empirical interest in end of life studies, it has typically been in their capacity as 'carers' or in relation to their views about care provision. This is perpetuated in palliative care literature where, while there is work concerned with the role of the family *vis a vis* end of life, relationality and the way in which behaviour and choices are negotiated *together* is under-theorised. Few studies, if any, make *everyday* family living the prime focus of investigation. Instead, family is conflated with care-giving, emphasising the boundaries between formal and informal care; relationships with health care professionals; and the perceptions and experiences of family care-givers in life-threatening/ terminal illness contexts (see James *et al.*, 2009; Phillips and Reed, 2009).

This emphasis in palliative care literature is further reflected in practitioner and clinical-based literature, where conceptualising the family as 'a unit' of care is widely accepted and established as a key principle in family systems nursing (Bell, 2009). In hospice and palliative care learning and practice, family members are thus not only seen as carers, but as 'second order patients' (Kissane and Bloch, 2002: 2). Such a way of thinking about family reproduces the ideas found in family systems theory, where family experiences are understood in terms of functionality and the effect(s) illness and death have upon familial roles and stability (Walsh and McGoldrick, 2004). This perspective neglects the fluidity of what constitutes families and what goes on 'in' them (Rosenblatt, 1994). In other words, it ignores how family is 'done' at the end of life.

In shedding some light on the everyday ways in which the end of life is negotiated between family members this paper thus empirically illuminates family practices in different settings and the way in which decisions about 'doing' healthcare and everyday life are made *between* people. In other words, it highlights the *relational* ways in which the protracted period of the end of life is navigated, negotiated and experienced by families, illustrating the essential contribution that family sociologists can make to contemporary understandings of death and dying, and vice versa.

The empirical studies

This paper originates from a themed symposium organised by the authors under the remit of the BSA Death, Dying and Bereavement study group where they discussed their respective theoretical, empirical and policy work in this area and identified insightful connections in their methodological and substantive focuses. These conversations formed the basis of a joint endeavour to revisit existing datasets, refine conceptual thinking, and craft a paper that reflected on the applied relevance of sociological family theory, namely family practices, for the end of life.

In the empirical sections that follow we draw on data from two studies: the first (A) conducted by Ellis (2010), a theoretical examination of family at the end of life; the second (B) by Borgstrom (2014) which focused on end-of-life care policy and practice. Study A primarily sought to explore how everyday family life is pursued when someone in the family has a life-threatening or terminal illness. It used family practice(s) as a conceptual lens to reveal relational aspects of nearing the end of life at home and when staying on a hospice inpatient unit (ward). Using an ethnographic approach, Ellis completed 175 hours of participation observation and conducted 39 in-depth interviews with relatives from 9 different families recruited via the hospice's day care service based

in the North of England. Interview transcripts and fieldnotes were coded and analysed using a narrative approach to thematic analysis (Riessman, 2008). This paper draws on observational data from Study A, gathered during periods spent with families at the hospice.

In contrast, study B specifically examined the idea of 'choice' in English end-of-life care because of the prominence of this concept in national policy at the time. It involved examining how choice was discussed and enacted in policy and practice through an analysis of policy documents related to end-of-life care. This was complemented by over 50 hours of observation of policy-related events, and 250 hours of participant-observation in clinical settings, and disease-related and carer support groups in the South of England. In addition, Borgstrom carried out over 100 semi-structured interviews with policy makers, healthcare professionals, patients and their families/carers (the majority of whom were receiving organised end-of-life care) to understand how people perceive, discuss, and enact 'choice'. A longitudinal element of the study generated data about how people live towards the end of life. This involved spending time with 10 individuals/couples recruited through support groups, care homes, or hospices who were interviewed and visited multiple times over 14 months to ascertain if and how discourses around choice were reflected in their everyday experiences. During the study, field notes were written following observations and interviews, and the entire dataset was analysed using ongoing ethnographic and contextual analysis. This paper draws on the data from the longitudinal aspect of Study B.

Participants in both studies provided consent [1] and all names and study sites have been anonymised beyond their geographical location identified above, as per

conventional BSA ethical guidelines (2017). To undertake the research for both studies, all appropriate NHS (National Health Service) ethics and local governance approvals were obtained.

The family practices theoretical framework utilised in this paper was developed by Ellis (2010). In this paper data from both studies is used to advance and extend the applicability of family practices in understanding some of the relational processes of the end of life and, in turn, how these can inform sociological research, national policy and frontline practice. In order to do so we strategically reviewed each study dataset to identify and select prominent examples that could illustrate our argument. This was purposeful to demonstrate the applicability of family practice to the experience of 'living' at the end of life, to illustrate how sociologists can contribute to future end of life research, policy and practice from a relational vantage point[2].

With Woodthorpe, the process of interrogating these examples involved identifying what families were doing at this time as well as reflecting on their dialogue about their 'doings'. This process required discussion about the data samples which pushed our collaborative analysis beyond what had previously been illuminated in Ellis (2010) and Borgstrom (2014). Thus working in this way we began to 'translate' the studies into one another by using an analytical approach that resonates with the aims of meta-ethnography (Noblit and Hare, 1988).

Study A: Doing family on a hospice ward

Physical changes experienced towards the end of life often require symptom-management or pain-control and can involve gradual or rapid periods of deterioration as well as an eventual phase of active dying. Managing these physical changes means

that sometimes a dying person needs to receive institutional care. This can have an impact on everyday family life and involve the ill person and their family traversing between different 'landscapes of care' (Milligan and Wiles, 2010; Milligan, 2009). When places of care change, it is possible to explore how at the end of life families are (re)produced in embodied and spatial terms as they experience 'doing' family in a more public and less familiar site of daily life, such a hospital or hospice ward (see Varley, 2009). In Study A this was clearly the case for one adult son (Vince) who visited the hospice to see his father Don, a patient in his 80s. Ellis recorded the following about one of Vince's visits:

'He spoke a little about the artificiality of visiting... He went on to talk about the ill family member being removed from the family as Don was - he said that 'they become an activity' for other members to complete - the going to visit. They [Don] aren't taking part in family activities any more, they are the activities'.

Discussing the artificial sense of interaction with his father that he felt during his visits, Vince implied that Don's place within the family had become both physically and relationally dislocated at this time. In the unfamiliar quasi-public/ quasi-private space (Morrill et al., 2005) of the ward environment, Vince was more conscious of how he related to his father through the (rather performative) practice of visiting, and (re)produced their everyday relationship.

At times this sense of family visibility also involved a heightened awareness of surveillance as was demonstrated in the case of Rob, a patient in his 60s who was visited regularly by his wife Mabel. The couple were both keen smokers and as the following field notes suggest, they were aware that their movements around the ward,

necessitated by wanting a cigarette, involved a rather public display of this particular shared practice.

'All the time we are talking I sense that Rob is eager to go for a cig (cigarette) - he keeps gazing towards the patio doors and keeping an eye on the pace of the rainfall - hoping for a suitable break to... pop out and have a puff. Mabel teases him about this and with a more serious tone she tells him that it might be best to wait for the doctor to go because he wouldn't approve of him going out - 'he might tell you off'. Mabel's comment about it not being the same as being at home pops into my mind as I watch them trying to negotiate what is usually a very normal, mundane part of their everyday life into the physical and moral regimes of the hospice as a particular institutional space...Later I spot the two of them organising Rob's trip out onto the balcony...Earlier Mabel had said to me that she would be careful to pick up all the [cigarette] tab ends and the two of them talked about needing to search Mabel's handbag for a carrier [bag] to put them in.

Rob and Mabel indicated how mundane family practices were both disrupted and more self-consciously experienced in the ward environment. Whereas smoking could (usually) occur spontaneously within their home and with far less orchestration, they were aware that doing this on the ward would disrupt the everyday order of the institutional setting, and was potentially subject to scrutiny. Yet for Rob and Mabel, recognising and supporting each other's need to smoke was a way of 'doing' family while Rob was an inpatient in the hospice: it became a deliberate way to continue to enact and reinforce their relationship, to 'do' their everyday family when in another setting.

There were other occasions where families deliberately (re)produced and enacted their activities from home on the ward and, sometimes, challenged how comfortable staff felt in the presence of such family practices. For example during the build-up to a night shift, when a family decided to stay with a patient, Archie, Ellis recorded the following:

'They [staff] started to talk about Archie's daughter specifically and said that they found it strange that she gets changed into her pyjamas and walks around the place in them. They tell me that she did this even before she knew they were stopping last night... Later... she [the daughter] emerges from Archie's room in her pyjamas and asks us if we want a drink - she is going to make herself and her mum one. We all decline and she wanders up to the tea-bar by reception - again she is bare foot.'

In this instance while a hospice inpatient service leaflet described the ward as offering 'a homely environment to all', this particular practice - wearing pyjamas – appeared to be regarded as an 'excessive' display of family practice by staff. This discomfort was not limited to pyjama wearing: staff also discussed how Archie's wife sat beside his bed with her feet resting upon it. Whilst this indicated intimacy and familiarity, they worried it might intrude on Archie's personal space.

By virtue of being in an institutional setting the most 'appropriate' way to 'do' family thus became contested. Although the ward was clearly *intended* to be a space for families to be together and staff strived to make everyone feel 'at home', mundane everyday family practices enacted and negotiated in this environment revealed the difficulty of actually *doing* family life towards the end of life as care settings changed. This enacting of practices also highlighted their familial significance as people worked *together* to create a sense of everyday family life.

Negotiating continuity in, and even extending, everyday family life in end of life care settings was especially important and affirming for some participants. Such an extension of family practice was described by Linda when she explained that being at the hospice had *created* time and opportunity for family activity that otherwise would feel rushed when juggling the usual activities of daily life at home. Linda and her family spent a prolonged period of time at the hospice visiting Linda's mother Molly, and on one occasion Ellis sat in a communal area with Linda whilst she made her young daughter a dancing costume. Ellis noted that:

'Linda has a needlework project on the go and it is spread out across the floor. She, I and Rachel (another patient's relative) are sat on the floor around it and Shelly (Linda's sister) is in one of the comfy chairs beside us. The outfit is a dancing costume which Linda's daughter is going to wear to a competition which is coming up. Linda reflects that she'd probably have felt too busy to do this at home.'

For families like Linda's that decide to stay at the hospice around the clock when a family member is approaching the end of their life, the sense of disruption to familiar family routines can be especially marked. Linda described it as being in 'a bubble'. However, as Linda further showed, this was not always experienced negatively as some family practices were transferred into the hospice space with a reaffirmed sense of value because there was time to experience 'doing family' more deliberately and consciously. Moreover, as was the case with Linda and her daughter, the transference of family practices between sites of care could also help to sustain relationships among family members based at the hospice most of the time and those family members who visited less frequently (for example, young children).

Before moving onto Study B, it is important to note therefore that the empirical examples from Study A demonstrate the displaced and ‘emplaced’ nature of family practices (Milligan, 2009) at the end of life, and how these may transfer, transition, change or be disrupted. Paying analytical attention to these practices enables a more in-depth understanding of how family is (re)produced at the end of life, along with the ways in which some of these everyday familial practices come under increased surveillance.

Study B: Everyday family decisions towards the end of life

Study B explored some of the choices that individuals and their families were making together at home as the end of life drew nearer. Many of these were not ‘big’ care decisions that healthcare professionals are typically interested in, but more everyday concerns that involved how families interacted and lived within their homes.

Related to this, three issues emerged. First, whilst death and dying (including declining health in the context of life-threatening illness) was used in interviews to talk about changes in everyday family practices, it was not always central to people’s lives and how they articulated what their everyday life was about. Second, social relationships, particularly with key other persons (usually a spouse, adult child, or ‘friend that is like a sibling’ as people described it), were very important in how individuals nearing the end of their life defined themselves and their daily activities and purpose. Third, these social relationships were often at the core of decision-making, influencing enactments of ‘choice’ about living towards the end of life with regard to things like care, in its broadest sense.

The intersection of these three issues was most vividly illustrated in discussions with an older couple about the prospect of visiting one of their adult children in another part of

the country, several hours away. William and Florence lived in sheltered housing: self-contained retirement housing with emergency alarm systems and home adaptations, such as a stair lift. They both expressed how pleased they were to have had the 'foresight' to move into this house before William was diagnosed with Parkinson's disease. Since moving into sheltered accommodation, their adult children had moved some distance away, and William and Florence tried to visit them each at least once a year. This particular year the plan was to visit their son 'up North' in September, but both Florence and William had reservations about the trip as William's condition – although not terminal at the time – was noticeably deteriorating, as field notes documented:

'His legs are getting worse', Florence whispered to me as William continued to smile at me, not quite hearing what she was saying. Speaking louder: 'They son and daughter-in-law] have a lovely house but to get in and out – they are on a hill – there are all these lovely stone steps. I'm worried he may trip. Or even me! Because of these steps, we can't really get out, not even to go get the papers, which is all we do when we are there any way as both of them [son and daughter-in-law] have to work. It is not very practical with his walker. We [William and Florence] keep talking about it and we don't want to go and be idle ducks. 'We can do that here', William interjected and we all chuckle.'

Originally suggesting that it was risky given William's declining condition, William and Florence further explained that their reluctance to negotiate the steps left them feeling trapped in their son's house without their daily comforts and routines. When asked what they were going to do as neither of them wanted to go, Florence said that she would have to tell her daughter-in-law – playing down the real concerns by explaining that they

‘don’t want such a long journey’ rather than being more honest and ‘alarm them about [our] health’.

As the discussion progressed over weeks, William began to suggest that not visiting their son was symbolic of his general deterioration, and his and Florence’s increasing reliance on each other. By this point, besides providing help with medication and getting dressed, William often relied on Florence to rephrase what others had said or what was on the television so he could follow conversations; her responses therefore often seem to capture what they both wanted. The decision to not visit their son further revealed the extent to which choices around William’s condition as he neared the end of his life were made very much together; resulting in their ceasing to be two individuals and becoming instead a single entity, a conjoined couple. Making this decision together enabled them to continue with, and conceal, their interdependent ‘day-to-day’ family life as they saw it.

Another example of relational decision-making could be seen in the case of Tony and Gayle. Tony was in his early 60s and had recently been diagnosed with several conditions affecting his major organs. Doctors were cautious about his overall prognosis and how close he was to the end of his life. Despite this, he was receiving ‘active treatment’ and his doctors were keen to discover the causes of new, and unexplained, symptoms. Divorced with several adult children, none of whom lived at home with him, Tony was in a long-term romantic relationship with Gayle. Gayle was in her mid-80s and maintained her own apartment a 10-minute walk away from his house. Since Tony had become ill, Gayle regularly stayed over and had become his main caregiver. Crucially, the couple were aware that their relationship was routinely not recognised as legitimate,

or worse, some healthcare professionals, family and friends assumed it was exploitative because of the age gap.

The way in which Tony and Gayle made decisions about doing family activities together (or not) is best exemplified in an exchange they had about their separate living arrangements. At the 'most intense points' of Tony's illness, as he described it, Gayle was 'stopping over' at his house five to six nights a week, only going back to her home to water the plants and check the post. She would sometimes share his bed or sleep in the second bedroom. Gayle's daughter (who was the same age as Tony) had suggested that Gayle move in with Tony, to reduce the need to maintain two households and to enable her mother to have 'her things with her all the time'. Gayle and Tony, somewhat proudly, recounted how they had openly discussed this between the two of them - including deliberating over the practical complications they experienced as a result of having two homes. They each stated their desire to maintain the shared spaces they could co-habit together but also to have somewhere to retreat to be alone and thus decided to keep both houses, even if Gayle only visited hers once a week. Sharing this information with Borgstrom was important to the couple as a way of demonstrating their ability to be 'independent-dependants', knowing that this aspect of their relationship (maintaining separate homes) often caused others to question the genuineness of their connection to one another.

Several weeks later, it became apparent there were additional reasons why the couple kept two homes as when Tony's children came to visit, Gayle did not feel 'welcome enough' to stay at his home. It was as if she was 'intruding on their family life'. According to them both, Tony's children 'felt uncomfortable' about their relationship. They did not understand how it operated and how it would affect their own relationship with their

father, both now and in the future. This was particularly 'trying' for Gayle and so she retreated to her own apartment when they were visiting, only checking in on him to make sure his health was okay. In addition, Gayle did not feel it was 'right' for her children to stay at Tony's house when they came to visit her, as in her mind they had 'no claim to that space'. Paradoxically, these periods of enforced separation, to accommodate adult children, meant that their children did not necessarily see how Gayle and Tony 'did' family life together day-to-day, something which may have helped legitimise their relationship within the wider family.

The complexity of their family practices became particularly problematic when Tony needed to identify a next of kin. Gayle often accompanied him for his medical tests and treatments but, as she was not Tony's wife, she could not call and request test results on his behalf. Despite having been in a relationship for years, maintaining different addresses meant that the GP practice did not consider their relationship as 'legitimate' as they were not co-habiting partners. When asked explicitly about 'kin', both Tony and Gayle chose to name their children, as they considered this would be less problematic. This was despite both stating that their children knew less than them about their health and preferences. These were things they shared only with each other, often mulling over issues as they drank tea or juice on the sofa or washed dishes together in the kitchen.

Importantly, in both couples, choices about family practices towards the end of their lives were shared, with them all saying things like: 'this is what we both want'. When facing their respective bodily declines, for both couples 'I' became 'we'. In so doing their experiences highlight the relational contexts of decision-making as part of managing everyday life during life-threatening illness. In both examples, the couples discussed

how the way they operated as a family had shifted – the ways in which their families were ‘done’ changed – generating a new ‘day-to-day’ as Florence described it. How they related to different activities and jointly owned decisions became a tool through which they could articulate to themselves and others their intentions and relational commitments. By paying attention to the relational dynamics within families revealed by a closer examination of family practices in these examples, the sociological lens here contributes to countering social and medical narratives that promote individualism in decision-making at the end of life (Borgstrom, 2014). It does this by demonstrating that decisions are influenced by multiple people over time considering a range of factors. They are actively, consciously and creatively made *between* people, (re)affirming and (re)producing their everyday familial relationship(s).

Discussion

The data presented in this paper demonstrate some of the ways in which family is done, displayed, (re)produced and experienced in end of life contexts. Nearing the end of life, as the paper shows, is, and can be, full of very mundane family practices: practices which are transferred to institutional settings whereby they are experienced more consciously, may come under increasing surveillance and can also be (re)affirmed as they get lost in the bus-iness of everyday life beyond the hospice walls. Elsewhere at home, decisions about what to ‘do’ in everyday life are shared, as couples become a single entity working in the best interests of both. In all cases, the end of life is a mutual and dynamic experience, continually negotiated and enacted between family members. The sociological conceptualisation of family practices is thus a useful conceptual lens through which to empirically explore different institutional and domestic sites of

everyday family life and decision-making when an individual is living towards the end of their life. This requires an acknowledgement that individuals do not approach the end of their lives in isolation; dying over an increasingly protracted period of time is a social *and* a relational process and experience. Utilising the concept of family practices has therefore enabled us to demonstrate how the end of life is embedded and enacted within the everyday lives of dying people – an approach which is under-developed in sociological scholarship on the end of life, and a part of everyday life that is not included in sociological theorising of the family. The examples discussed also illustrate how relationships continue and evolve in spite of declining health and the possibility of increased surveillance by medical professionals. This provides a counter to sociological theories about illness and the end of life being about isolation, increasing individualisation and institutionalisation, and the severing of social ties.

Such a social and relational approach presents an ideological and practical challenge for end of life national policy and frontline practice where individualised discourses about decisions and care are most often taken-for-granted and authoritatively reproduced. Whilst recent policy conversations seek to take into account how relationships influence preferences around care and end of life decision-making (Henry, 2015), the primary focus in policy guidance remains overwhelmingly on the dying individual and their place of death (Teggi, 2018). Policy models and approaches to delivering care at the end of life fail to envisage and reflect the relational way in which people nearing the end of their life continue to live, and make decisions about how they want to live, *with* others. These ‘others’ are not just secondary patients orientated around the person at the end of their life; negotiations and actions happen *between* family members. As this paper has shown, this includes the way in which family

practices are (re)enacted in institutional settings; and how pronouncements about living arrangements are made.

Sociologists, who work within the rubric of family and personal life, and those specialising in death and dying, can (and need to) contribute to end of life policy and practice in a number of ways. First, focusing on the 'doing' of family would revolutionise how families are regarded in end-of-life care, with family not regarded as secondary to patients (or even second order patients) but *central* to policy and practice (Brown and Walter, 2014). This would include a recognition of another's input (or not) into decisions, the domestication of care settings (as shown in this paper), and acknowledging how choices about how to live at the end of life are made in the best interests of more than one person - for example in the case of William and Florence, deciding what was best for them as a *couple*, rather than two individuals. Second, a sociological contribution that highlights the fluidity and negotiated way in which relationships and families are practiced could help resist normatively framing the family as a collective and static unit that functions solely to provide care for the dying person. Such insight could include identifying how out-of-date normative conceptualisations of linear family structures overlook the way in which family practices at the end of life both reflect and contribute to the making and unmaking of family (Finch and Mason, 2000; Woodthorpe and Rumble, 2016; 2017). Third, understanding how family is 'done' towards the end of life could assist in bridging the existing gap between rhetoric and practice in providing 'good deaths' within the family context (Kissane, 2016).

Core to this potential is the importance of treating, acknowledging and accommodating family at the end of life as a fluid and shifting concept, not least because understandings of family *will change* as a result of a family member dying and their eventual death.

Obviously after a death familial 'positions' change, for example adult children become orphans (Barbour *et al.*, 2013), and so too do care obligations (Bruhn and Rebach, 2014). But everyday life also changes - it does not cease when someone is approaching the end of their life or after they have died. They and those around them are *living* until and beyond their death. Recognising and providing space for the discussing and *doing* of family in everyday life towards the end of (a) life enables a shift from a policy and practice focus on the family 'unit' or as a nexus of a central individual and their orbiting familial relatives, towards a more open and inclusive concept of family that can further incorporate wider family, friends and community members. Resonating with Kellehear's (2005) conceptualisation of compassionate cities and the shifting of expertise on the end(ing) of life and dying from institutions into communities, such an appreciation moves the end of life out of the realm of medical discourse and into the everyday world of families. The end of life thus becomes one that is more than the specific 'dying' process and instead is a prolonged period of time that is characterised by creativity and how family is actively 'done' *between* people, just like any other everyday family practice. Such emphasis on the mundanity of family practices at the end of life may in turn de-sanctify death and open up sociological and public discussion about dying which, despite the best efforts of scholars and charities, still remains in part sequestered (Woodthorpe, 2017).

Conclusion

This paper has demonstrated ways in which family practices take place at the end of life, for example in the (re)production of the doing of familial relationships in a hospice and the way in which decisions regarding care are made together. In emphasising the applicability of family practice theory to the end of life, it has made a case for sociologists

to lead the way in advancing research, policy and practice that moves beyond a highly individualised understanding of dying. In so doing, greater acknowledgement is required of the ways in which families are actively and creatively being made and (re)produced at the end of life. At its core, the end of life still involves everyday *living*.

Acknowledgements

The authors are listed in alphabetical order by surname and have contributed equally to the production of this article. They would like to thank the research participants and study sites involved in their respective research projects. The authors would like to thank Tony Walter and colleagues at the University of Sheffield for reading early drafts of the paper, and the anonymous reviewers for the journal who all provided constructive and helpful feedback and suggestions. Borgstrom would like to thank her doctoral supervisors for their support and Ellis would like to thank Jenny Hockey for her supervisory support.

Funding

Ellis' research was funded by an Economic and Social Research Council Studentship; grant reference PTA-030-2005-00154. Borgstrom's research was funded through a National Institute of Health Research (NIHR) Collaborations for Leadership in Applied Health Research and Care (CLAHRC) for Cambridgeshire and Peterborough doctoral scholarship held at the University of Cambridge.

Notes

[1] Study A: whilst undertaking observation on the hospice ward, in cases where patients lacked capacity to consent this required sensitive negotiation with families. If relatives stated they wanted to be involved, they became the Ellis' main focus in observations and consent was continually revisited.

[2] Whilst this paper is an example of theory-verification by using multiple data sets from different contexts, both studies were originally not deductive in nature.

References

- Barbour, R., Komaromy, C., Morgan-Brett, B., and Barbour, M. (2013). *Re-conceptualising adult orphans: a scoping literature review*. Presented at the BSA DDB Symposium, 15 November, London.
- Beck, U. (2000) Zombie categories (interview with Ulrich Beck). In: J. Rutherford (ed.) *The Art of Life. On Living, Love and Death*. London: Lawrence & Wishart. p. 35-51.
- Beck, U. and Beck-Gernsheim, E. (2004) Families in a runaway world. In: J. Scott, J. Treast and M. Richards (eds.) *The Blackwell Companion to The Sociology of Families*. Oxford: Blackwell. p. 499-514.
- Bell, J. M. (2009) Family systems nursing re-examined. *Journal of Family Nursing* 15 (2), 123-129.
- Bennett, T. and Silva, E. B. (2004) Everyday life in contemporary culture. In: E. B. Silva and T. Bennett (eds.) *Contemporary Culture and Everyday Life*. Durham: Sociology Press. p. 1-20.
- Borgstrom, E., 2014. *Planning for Death? An Ethnographic Study of English End-of-Life Care*. Cambridge: University of Cambridge.
- Borgstrom, E., 2015. Planning for an (un)certain future: Choice within English end-of-life care. *Current Sociology*, 63(5), 700-713.
- Borgstrom, E., 2016. End of life care strategy and the Coalition Government. In L. Foster & K. Woodthorpe, eds. *Death and Social Policy in Challenging Times*. Basingstoke: Palgrave Macmillan. p.35-52.
- Broom, A. and Kirby, E. (2013) The end of life and the family: hospice patients' views on dying as relational. *Sociology of Health & Illness* 35 (4), 499-513.

Broom, A., Kirby, E., Kenny, K., MacArtney, J. and Good, P. (2016) Moral ambivalence and informal care for the dying. *The Sociological Review* 00, 1-18.

Brown, L. and Walter, T. (2014) Towards a social model of end-of-life care. *British Journal of Social Work* 44 (8), 2375-2390.

Bruhn, J.G., and Rebach, H.M. (2014) *The Sociology of Caregiving*. New York: Springer.

British Sociological Association (2017) Statement of Ethical Practice. Available from: <https://www.britsoc.co.uk/ethics> [accessed 28.2.18]

Department of Health (2008) *End-of-life care Strategy: promoting high quality care for all adults at the end of life*. The Stationary Office, London, England.

Ellis, J., 2010. *Family practices during life-threatening illness: exploring the everyday*. Sheffield: University of Sheffield.

Ellis, J., 2013. Thinking beyond rupture: continuity and relationality in everyday illness and dying experience. *Mortality*, 18(3), 251–269.

Ellis, J., 2018. Family food practices: relationships, materiality and the everyday at the end of life. *Sociology of Health & Illness*, 40(2), 353–365

Field, D. (1996) Awareness and modern dying. *Mortality* 1 (3), 255-265.

Finch, J. (2007) Displaying family. *Sociology* 41 (1), 65-81.

Finch, J. and Mason, J. (2000) *Passing On: Kinship and Inheritance in England*. London: Routledge

Gabb, J. (2008) *Researching Intimacy in Families*. Basingstoke: Palgrave Macmillan.

Henry, C. (2015). *What's Important to Me: A Review of Choice in End-of-life care*. London: The Choice in End-of-life care Programme Board.

James, I., Andershed, B. and Ternstedt, B-M. (2009) The encounter between informal and professional care at the end of life. *Qualitative Health Research* 19 (2), 258-271.

Jamieson, L. (1998) *Intimacy: Personal Relationships in Modern Societies*. Cambridge: Polity Press.

Kellehear, A. (2005) *Compassionate Cities: Public Health and End-of-life Care*. London: Routledge.

Kellehear, A. (2008) Dying as a social relationship: A sociological review of debates on the determination of death. *Social Science & Medicine* 66 (7), 1533-1544.

Kellehear, A. (2014) *The Inner Life of the Dying Person*. New York: Columbia University Press.

Kissane, D. W. (2016) 'The Challenge of Family-centred Care in Palliative Medicine', *The Annals of Palliative Medicine*, 5 (4): 319-321.

Kissane, D. W. and Bloch, S. (2002) *Family Focussed Grief Therapy*. Maidenhead: Open University Press.

May, V. and Dawson, M. (2018) 'Families and Relationships' e-Special Issue Introduction. *Sociology* 1-10.

Miller, D. (2017) *The Comfort of People*. Cambridge: Polity Press.

Milligan, C. (2009) *There's No Place Like Home: Place and Care in an Ageing Society*. London: Routledge.

Milligan, C. and Wiles, J. (2010) Landscapes of care. *Progress in Human Geography* 34 (6), 736-754.

Morgan, D. H. J. (1996) *Family Connections. An Introduction to Family Studies*. Cambridge: Polity Press.

Morgan, D. (2004) Everyday life and family practices. In: E. B. Silva and T. Bennett (eds.) *Contemporary Culture and Everyday Life*. Durham: Sociology Press. p. 37-51.

Morgan, D. H. J. (2011) Locating 'Family Practices'. *Sociological Research Online* 16 (4) 14. Available from: <http://www.socresonline.org.uk/16/4/14.html>

Morgan, D. H. J. (2013) *Rethinking Family Practices*. Basingstoke: Palgrave Macmillan.

Morrill, C., Snow, D. A. and White, C. H. (2005) *Together Alone*. Personal Relationships in Public Places. London: University of California Press.

Noblit, G. W. and Hare, R. D. (1988) *Meta-Ethnography: Synthesizing Qualitative Studies*. London: Sage.

Peel, E. and Harding, R. (2015) VIII. A right to 'dying well' with dementia? Capacity, 'choice' and relationality. *Feminism & Psychology* 25 (1), 137-142.

Phillips, L. R. and Reed, P. G. (2009) Into the abyss of someone else's dying. The voice of the end-of-life caregiver. *Clinical Nursing Research* 18 (1), 80-97.

Ribbens McCarthy, J. and Prokhovnik, R. (2014) Embodied Relationality and Caring after Death. *Body & Society* 20 (2), p. 18-43.

Riessman, C. K. (2008) *Narrative Methods for the Human Sciences*. London; Sage.

Rosenblatt, P. C. (1994) *Metaphors of Family Systems Theory*. London: Guilford Press.

Rosenil, S. and Ketokivi, K. (2015) Relational persons and relational processes: developing the notion of relationality for the sociology of personal life. *Sociology* 50 (1), p. 143-159.

Samarel, N. (1995) The dying process. In: H. Wass and R. A. Neimeyer (eds.) *Dying. Facing the Facts*. 3rd edition. London: Taylor & Francis, p. 89-116.

Seale, C. and Cartwright, A. (1994) *The Year Before Death*. Aldershot: Ashgate Publishing.

Small, N. and Hockey, J. (2001) Discourse into practice: the production of bereavement care. In: J. Hockey, J. Katz and N. Small (eds.) *Grief, Mourning and Death Ritual*. Buckingham: Open University Press. p. 97-124.

Smart, C. (2007) *Personal Life. New Directions in Sociological Thinking*. Cambridge: Polity.

Strange, J-M. (2009) Historical approaches to dying. In: A. Kellehear (ed.) *The Study of Dying. From Autonomy to Transformation*. Cambridge: Cambridge University Press. p. 123-146.

Szmigin, I. and Canning, L. (2015) Sociological Ambivalence and Funeral Consumption. *Sociology* 49 (4), 748-763.

Teggi, D. (2018) 'Unexpected death in ill old age: an analysis of disadvantaged dying in the English old population', *Social Science and Medicine*, 217: 112-120.

Varley, A. (2008) A place like this? Stories of dementia, home, and the self. *Environment and Planning D: Society and Space* 26, 47-67.

Walsh, F. and McGoldrick, M. (2004) *Living Beyond Loss. Death in the Family*. 2nd edition. London: W.W. Norton & Company.

Walter, T. (1999) *On Bereavement. The Culture of Grief*. Maidenhead: Open University Press.

Woodthorpe, K. & Rumble, H., 2016. Funerals and families: locating death as a relational issue. *The British Journal of Sociology*, 67(2), pp.242–259.

Woodthorpe, K., 2017. Family and funerals: Taking a relational perspective. *Death Studies*, 41(9), pp.592–601.

Young, M. and Cullen, L. (1996) *A Good Death. Conversations with East Londoners*. London: Routledge.

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