Managing death: navigating divergent logics in end-of-life care

Simon Bailey<sup>1</sup>, Damian Hodgson<sup>2</sup>, Sarah-Jane Lennie<sup>3</sup>, Mike Bresnen<sup>3</sup> and Paula Hyde<sup>4</sup>

<sup>1</sup>University of Kent, Kent, UK
<sup>2</sup>University of Sheffield, Sheffield, UK
<sup>3</sup>Manchester Metropolitan University, Manchester, UK
<sup>4</sup>University of Birmingham, Birmingham, UK

Abstract Delivery of end-of-life care has gained prominence in the UK, driven by a focus upon the importance of patient choice. In practice choice is influenced by several factors, including the guidance and conduct of healthcare professionals, their different understandings of what constitutes ‘a good death’, and contested ideas of who is best placed to deliver this. We argue that the attempt to elicit and respond to patient choice is shaped in practice by a struggle between distinct ‘institutional logics’. Drawing on qualitative data from a two-part study, we examine the tensions between different professional and organisational logics in the delivery of end-of-life care. Three broad clusters of logics are identified: finance, patient choice and professional authority. We find that the logic of finance shapes the meaning and practice of ‘choice’, intersecting with the logic of professional authority in order to shape choices that are in the ‘best interest’ of the patient. Different groups might be able to draw upon alternative forms of professionalism, and through these enact different versions of choice. However, this can resemble a struggle for ownership of patients at the end of life, and therefore, reinforce a conventional script of professional authority.

Keywords: end-of-life care, institutional logics, patient choice, professional conflict, bureaucracy, informal work

Introduction

The last two decades have seen increasing attention paid to how we care for the dying (Mellor and Shilling 1993). Publications such as Gawande’s ‘Being Mortal’ (2014) have brought to prominence concerns linked to both the escalating cost of end-of-life care in ageing populations and the need to change how Western societies confront death. It is argued that this renewed focus on the end of life is partly driven by experts seeking to manage or control death and dying (McNamara et al. 1994, Walter 2014). Important questions are raised regarding what constitutes ‘good care’ at the end of life – where this should occur, how best to involve patients and carers in decisions, and how to control (i.e. reduce) costs (Seale 2000). Our paper shows that the attempt to answer these questions in practice places practitioners at
the intersection between competing professional and organisational ‘logics’ (Goodrick and Reay 2011, McDonald et al. 2013).

End-of-life care as a field produces several challenges to existing philosophies of health care (Iedema et al. 2005). When the final outcome is, by definition, the death of the patient, this runs counter to the deeply established norm in medicine that regards death as failure (Bishop 2011, Gawande 2014). End-of-life care is an aspect of care which also fits poorly with economic thinking which links health care to productive and active consumers/producers (Gill 2012). When the (rising) costs of health care are justified as an investment in a healthy and therefore productive society, end-of-life care stands as an anomaly and even weakens the ‘case for’ health care. The increasing tendency for mortality rates to be used to rate the quality of hospital care also shows how it can fail to align with the interests of doctors and managers.

An increasingly prevalent discourse is that the failure to ‘manage’ death frequently leads to ‘unnecessary’ and intrusive medical procedures which are unreflexively initiated, typically in hospital settings, to extend life at any cost (Davis 2015, Seymour et al. 2002). Such an ‘unmanaged’ death can be more distressing for both the person dying and their family. At the same time, it is claimed that such deaths are significantly more expensive than those ‘managed’ using formal mechanisms through which patients can be supported to die at home or in a care home (Curie 2012, Georgiou and Bardsley 2014). This is assumed to be more likely to constitute ‘a good death’ and, at the same time, a less expensive and better managed death. This is problematic as there is no robust evidence of the differential costs of delivering end-of-life care in different settings; however, moving care from hospital to home does appear to afford the opportunity to redistribute costs away from formal health settings.

The ‘good death’ narrative implies that patients and carers increasingly would, or should, prefer to remain in their own home, or a care home, to die. However, research has shown this to be an incomplete and often inaccurate picture, demonstrating that patient choice is more nuanced than the current narrow focus on patient preferred location of death (Hoare et al. 2015, Pollock 2015). This highlights a complex ethical relationship between professional and organisational concerns, and the achievement of end-of-life care that reflects patient choice (MacArtney et al. 2016). It is this relationship that our paper aims to address.

We build upon work which has described death as a ‘practical accomplishment’ shaped in part by the preferences of patients and families, but also by the affordances of particular contexts (MacArtney et al. 2016). Although both professionals and patients contribute to this accomplishment, our particular focus is on the manner in which professional interests and organisational boundaries become active mediators in shaping patient choice at the end of life. This presents a practical challenge and a moral dilemma: informing patients in order to guide their choices regarding their care ultimately influences the decisions patients make. While this process involves the interaction of numerous different professionals across health and social care, at the same time, it creates moral uncertainties and promotes contestation over ownership and responsibility.

End-of-life policy

In the UK, the rising prominence of end-of-life care in health and social care policy can be traced through several initiatives over the last decade (Department of Health 2008, NHS England 2014). Borgstrom and Walter (2015) identify two broad agendas at play: one focused on enhancing patient choice, largely driven by developments in palliative cancer care; the other focused on the promotion of more compassionate care at the end of life, motivated largely by scandals related to elderly care provision in the UK.

© 2020 The Authors. Sociology of Health & Illness published by John Wiley & Sons Ltd on behalf of Foundation for SHIL (SHIL)
One tangible outcome has been the emergence of policy consensus about what the characteristics of ‘good’ end-of-life care should be (Department of Health 2015a, 2015b). First, patients prefer to be close to home and more personalised care can be provided outside hospital. Second, the hospitalisation of patients near death increases the likelihood they will be subjected to more interventions for minimal benefit, producing a less peaceful death. Third, the needs and wishes of both the patient and their carers and family need to be taken into account. Finally, it is argued that good end-of-life care in accordance with these principles can be provided at lower cost. Following this rationale, it is clear that such care needs to be planned and managed to a significant degree. It is also clear that it requires the alignment of different objectives and interests and that this can be achieved without substantial compromise – an assertion which will be scrutinised later.

The practical impact of this shift in policy can be seen in greater guidance in this area, focused on planning, reduction (or at least redistribution) of cost and relocation. The focus in England from 2010 onwards has been on Advanced Care Planning (ACP), which seeks to identify those approaching the end of life, offering them the choice as to how they would like this to happen. A range of tools and measures have been implemented, many enshrined in initiatives such as the Gold Standards Framework (GSF), and incentivised, for example, by linking additional payments to GP practices for GSF activities (Shaw et al. 2010). Collectively, the impact of these has been substantial; the proportion of people in England who die in their ‘usual place of residence’ (i.e. their own home or a care home; routinely measured as Death in Usual Place of Residence [DiUPR]) rose steadily for 5 years from 2008 when the national strategy was launched and has since remained relatively stable (NEoLCIN 2014, 2018).

At the same time, the consequences of managing end-of-life care in practice have proved more controversial. The Liverpool Care Pathway (LCP), developed as a set of best practices drawing on care in the hospice movement, was translated into a protocol for other settings. However, following a media campaign, it was reviewed in 2013 and abandoned the following year (George et al. 2014, Neuberger et al. 2013), as it was perceived as too bureaucratic, lacking in empathy and compassion, and poor at enabling effective communication with patients and family (Watts 2012). As Broadbent (2013) noted: ‘clinicians should remember that no pathway, plan, or protocol can be a replacement for good clinical judgement, compassion and care’. However, its discontinuation was unpopular with those health professionals who conceived of it as important in prompting difficult conversations between providers, patients and families, which might otherwise not occur (Davies et al. 2014). Thus, tensions surfaced between health professionals’ desire for better support in normalising discussions about death, and the discontinuation of one of the most widely used tools helping providers achieve this (Watts 2012).

What this signals is the existence of conflict between ways of thinking about and planning for care that rely on formalised approaches to care planning driven by population health considerations; and the need for a patient- and family-centred, choice-led approach supported by knowledgeable and compassionate staff treating ‘the whole person’ (Di Leo et al. 2015). This raises deeper questions about trust and the underlying philosophy of care to which one ascribes, as well as the role of rational planning and management (George et al. 2014).

**Conceptualising end-of-life care**

Given its complex positioning within the healthcare and social care landscape, end-of-life care is also inherently inter-organisational and inter-disciplinary, requiring the routine and effective coordination of primary, secondary and community care alongside social services, voluntary
sector and other public services. Care may take place in a hospital, a hospice, care or nursing homes or at a person’s own home (or indeed a prison, a convent or elsewhere). Patients may be under the care separately or simultaneously of a family doctor, a consultant or specialist, hospital or primary care nurses, social care workers, district nurses, paramedics, allied health professionals, specialist palliative care professionals, and professional carers in residential and nursing homes, and of course their own carers, typically close relatives.

While not unique in this respect, end-of-life care is thus a field which cuts across established organisational and professional boundaries (Currie et al. 2009). The multiplicity of potential decision-makers, whose decisions are frequently interdependent, results in significant potential for miscommunication and confusion, but also in rivalry and struggles for professional dominance (Nancarrow and Borthwick 2005). The field is particularly complex owing to its uncertain status among other medical specialties with contested jurisdictional boundaries (Hibbert et al. 2003). Thus, one of the primary benefits of ACP and the GSF is that they enable conversations between professionals (Mahmood-Yousuf et al. 2008, Walshe et al. 2008). That said, such formal mechanisms alone cannot resolve long-engrained professional boundaries between doctors and nurses (Svensson 1996) or GPs and community nurses (Seale 1992).

In addition, delivering care through this complex process means balancing multiple objectives. End-of-life care might mean various things: to delay or prevent death, minimise pain, maintain dignity, minimise cost, and facilitate patient and/or carer/family preferences (Gjerberg et al. 2010). The priority given to each of these depends on the particular case but is powerfully informed by the professional involvement and orientation of different groups (Seale 1992, Walshe et al. 2008). Hence, some suggest that the quality of care is affected when the power of nurses is constrained (Asch et al. 1997, Costello 2006, Griggs 2002); whereas others suggest that GPs need to become more actively involved at the end of life (Shipman et al. 2008).

The issue of ‘patient choice’ is pivotal in recent policy in this area and sufficiently complex as to require consideration in more depth. At heart, the logic of patient choice is simple: incorporating patient choice through ACP enables patients to have a ‘good death’ (Borgstrom 2015: 702). This argument is widely supported with examples of disempowered patients who were not consulted or whose wishes were ignored by the professional/medical establishment (Balducci 2012, Belanger et al. 2011, Holdsworth and King 2011). It might be argued that patient choice rebalances the power relationship between clinician and patient, as ‘patient control over dying represents a challenge to the clinical judgement of health care professionals . . . (and) to their professional autonomy and power’ (Borgstrom and Walter 2015: 102). However, this logic is also firmly embedded in a neoliberal belief that people have the right to exercise choice in shaping service delivery to suit their needs, and also in the inherent moral worth of increasing the choices available to ‘service users’ (Barnes and Prior 1995).

In both policy and practice, however, what is meant by patient choice in end-of-life care is more narrowly constrained. Clearly, any kind of choice exercised is dependent on there being the funding and resources to deliver ‘preferred’ arrangements (Munday et al. 2007). Any choice is dependent upon the information and guidance offered to patients by those with expertise – healthcare professionals (Bryant et al. 2007). In practice, as Borgstrom argues: ‘there is a specific kind of choice that policy makers promote . . . [namely] the ability to die at home’. (Borgstrom 2015: 705).

There are also more fundamental challenges to the logic of patient choice in this context. End-of-life care is frequently administered in situations of significant fear, pain and confusion (McPherson et al. 2007, Seale 1995). Decisions taken are highly sensitive: it may be difficult for a dying person to express a preference to die at home given the burden this places on carers (McPherson et al. 2007); or to express a desire to die sooner despite the pain this would cause to close family (Seale 1995, Seymour et al. 2004); or indeed to choose not to choose
(Borgstrom 2015, Zimmermann 2004). This again highlights tensions between the neoliberal principle of patient choice inscribed in policy and the problematic reality (Borgstrom and Walter 2015).

If policy is to promote choice, then there is the need to appreciate the manner in which choices are afforded and excluded in the management of death and dying. It is not particularly useful here to frame these tensions in binary terms (e.g. management needs vs. professional values). Rather, following McDonald et al. (2013), we would argue that a more helpful way of understanding these organisational and professional complexities is to see them as being governed by different institutional logics.

Problematising policy with institutional logics

Institutional logics are constructed value systems which ‘provide taken-for-granted conceptions of what goals are appropriate and what means are legitimate to achieve these goals’ (Pache and Santos 2013: 973). Friedland and Alford (1991) introduced logics in an effort to emphasise external context alongside organisational and individual concerns. Core societal institutions are identified, such as the market, the family, the legal system, class structure, religion, representative government, science and the professions. Each has its overarching ‘logics’ or ‘master rules’ that prescribe and proscribe behaviour (Greenwood et al. 2014: 1214). Empirical work tends to focus beneath these ‘meta-logics’ (Fincham and Forbes 2015) at the meso-level of organisational field, industry and sector wherein specific logics are nested (Goodrick and Reay 2011). Thus, McPherson and Sauder (2013) identify a range of logics covering punishment, rehabilitation, efficiency and accountability which interact in the course of everyday conduct in a US court. In this regard, institutional logics are used to identify and understand consistencies in social forces which influence and structure action.

The value of this framing is less to explain situations where there is a single, dominant logic shaping individual and organisational practices, but rather to offer a means to understand settings where there are multiple coexisting logics in play (Thornton et al. 2012). The resultant struggle between distinct logics has been traced in various settings, to consider how, for instance, market logics challenge and supplant civil service logics in New Public Management reforms (Thomas and Davies 2005). Attention has more recently turned to how to track this struggle empirically, and explore how such struggles are resolved or how logics may co-exist: for instance, through the compartmentalisation of different aspects of work (Goodrick and Reay 2011) or through the hybridisation of logics (Hodgson et al. 2015, Pache and Santos 2013). Hence, institutional logics offer a means to understand change and difference, as well as continuity based on the securing of legitimacy at an institutional level (Greenwood et al. 2014, Suddaby 2010). Moreover, through their inscription in rules, values and practices, these logics are not ‘free-floating’, abstract ideas but are embedded within the power relations between different groups and constitute the means by which multiple versions of reality compete with one another (Mol 2002, 2008).

Institutional logics have proved an attractive approach for researchers seeking to conceptualise the complexity of healthcare systems (Goodrick and Reay 2011, Harris and Holt 2013, McDonald et al. 2013). The typical narrative for such work in the UK is of a growing challenge to the biomedical logic associated with clinical pre-eminence from rival logics – typically market logics associated with commercialism (Harris and Holt 2013: 63). We might therefore reconceptualise debates regarding choice, and ‘good’ end-of-life care by seeking to identify empirically how logics are mobilised by practitioners seeking to pursue their interests. The focus then becomes how such logics are enacted in practice, how the contradictions
between logics are worked upon by different groups, and what the outcome of this struggle is for the management of end-of-life care.

**Methodology**

The data presented here were generated at two different time-points approximately 5 years apart. The first point involved a 12-month mixed-methods study conducted in a large and demographically diverse conurbation in England between 2012 and 2014, funded by a regional healthcare trust. Informed initially by quantitative DiUPR data, the research combined individual interviews and focus groups to analyse the factors influencing the ability of services to manage place of death occurring across the region. As noted above, place of death has been articulated in policy as both a mechanism and signifier for the delivery of ‘good’ and ‘choice-led’ end-of-life care. The qualitative analysis presented here focuses on this relationship between ‘good’ care, place of death and choice, as framed and contested by professionals involved in the delivery of end-of-life care. The inclusion of patient and carer perspectives, although clearly important, was beyond the scope of this study.

The second study involved a return to the same context to supplement the original dataset and to take account of changes that had occurred in the interim. This was pertinent, as the first study had been conducted immediately after the passing of the Department of Health (2012), which had resulted in substantial changes regionally and nationally – for example, one of the trusts with whom the research was undertaken had doubled in size through incorporating community services. Changes were also underway specific to end-of-life care – notably, in the abandonment of the LCP.

In total, 21 individual interviews (9 from study 1 and 12 from study 2) and three focus groups (n = 16; all from the first study) were conducted across a single region (Tables 1 and 2). Interviewees were selected to cover the range of relevant organisations and professional groups. In total, 17 interviews and all three focus groups were recorded and transcribed. The remaining four individual interviewees (S1 P6–P9) were not willing to be recorded and so detailed notes were taken.

Transcripts and notes were subject to a multi-stage analytical process. In the first study, one team member conducted a detailed reading of the complete dataset, inductively coding into open categories (Strauss and Corbin 1990) using NVivo software. A coding structure was then collectively devised, through which data were organised into themes to link codes to factors relating to place of death. The identification of relevant factors brought to light broader issues concerning the sensitive and taboo nature of the subject, as well as issues to do with occupational boundaries, conflict and ownership of care. These were the issues around which the second round of interviews were structured and analysed, following on from the first dataset. Subsequently, taking the two sets of data together, we drew on the theoretical literature on institutional logics as a means of framing the analysis of boundaries and interests. We then refined the analysis, drawing out, comparing and contrasting the different logics at work in practices of end-of-life care as represented in our dataset. This generated the three logics discussed below: the financial logic, the logic of choice and the logic of professional authority.

**Contested logics in end-of-life care**

*Financial logic*

The financial logic focused on the cost of end-of-life care, often emphasising the financial burden of delivering this care in hospital settings. A more sophisticated argument within this logic
<table>
<thead>
<tr>
<th>Study number</th>
<th>Participant number</th>
<th>Job title</th>
<th>Organisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>S1</td>
<td>P1</td>
<td>GP</td>
<td>General Practice</td>
</tr>
<tr>
<td>S1</td>
<td>P2</td>
<td>Medical Director</td>
<td>Acute Trust</td>
</tr>
<tr>
<td>S1</td>
<td>P3</td>
<td>GP</td>
<td>General Practice</td>
</tr>
<tr>
<td>S1</td>
<td>P4</td>
<td>General Manager</td>
<td>Care Home</td>
</tr>
<tr>
<td>S1</td>
<td>P5</td>
<td>Medical Director</td>
<td>Clinical Commissioning Group (CCG)</td>
</tr>
<tr>
<td>S1</td>
<td>P6</td>
<td>GP and Urgent Care Lead</td>
<td>General Practice and CCG</td>
</tr>
<tr>
<td>S1</td>
<td>P7</td>
<td>Consultant Geriatrician</td>
<td>Acute Trust</td>
</tr>
<tr>
<td>S1</td>
<td>P8</td>
<td>GP and Associate Medical Director</td>
<td>General Practice and Mental Health and Community Trust</td>
</tr>
<tr>
<td>S1</td>
<td>P9</td>
<td>Lead palliative care nurse</td>
<td>Mental Health and Community Trust</td>
</tr>
<tr>
<td>S2</td>
<td>P1</td>
<td>Service Lead</td>
<td>Nursing Home Service</td>
</tr>
<tr>
<td>S2</td>
<td>P2</td>
<td>Director of Clinical Services</td>
<td>Hospice</td>
</tr>
<tr>
<td>S2</td>
<td>P3</td>
<td>Ward Manager</td>
<td>Acute Trust</td>
</tr>
<tr>
<td>S2</td>
<td>P4</td>
<td>Senior Sister</td>
<td>Acute Trust</td>
</tr>
<tr>
<td>S2</td>
<td>P5</td>
<td>Assistant Service Manager</td>
<td>National Social Care Charity</td>
</tr>
<tr>
<td>S2</td>
<td>P6</td>
<td>Practice Development Facilitator</td>
<td>Hospice</td>
</tr>
<tr>
<td>S2</td>
<td>P7</td>
<td>Assistant Director of Nursing for Palliative End-of-life Care</td>
<td>Care Alliance</td>
</tr>
<tr>
<td>S2</td>
<td>P8</td>
<td>Lead Nurse for Palliative and End-of-life Care</td>
<td>Care Alliance</td>
</tr>
<tr>
<td>S2</td>
<td>P9</td>
<td>Mental Health Outreach and HITTS Nurse</td>
<td>Community Mental Health</td>
</tr>
<tr>
<td>S2</td>
<td>P10</td>
<td>Head of Practice Development</td>
<td>Hospice</td>
</tr>
<tr>
<td>S2</td>
<td>P11</td>
<td>Matron for Adult Supportive and Palliative Care</td>
<td>Acute Trust</td>
</tr>
<tr>
<td>S2</td>
<td>P12</td>
<td>Consultant Physician &amp; Clinical Lead for Acute Medicine</td>
<td>Acute Trust</td>
</tr>
</tbody>
</table>
went further and emphasised the excessive costs where care was not planned or ‘managed’ effectively. Hence, this was often used to justify more deliberate and anticipatory management of care. Statements following this logic often made a virtue of dealing with the reality of healthcare and perpetual financial pressures; or saw this as a game which must be played in order to convince key decision-makers, whose priorities were seen to be as primarily financial. A marked difference could be observed regarding comments about financial pressures between the two periods of data collection, with participants in the second phase commonly referring to a funding ‘crisis’:

The National Health Service is always going to be short of money and it’s in crisis at the moment, and if we’re looking after people who are dying, and dying isn’t something that is talked about ... There are other diseases that are up there ... It’s a very medical model, isn’t it, that from a medical perspective people are trying to cure people. Death is still seen sometimes as a failure. (S2 P6)

The above quote also draws a relationship between the financial logic, the professional authority logic which draws on an acute or disease-based model, and a professionalised taboo of death, which are all matters we will discuss below.

The financial logic was typically not the first explanation put forward in practitioner discussions or, where it was, it was generally ascribed to organisational interests:

Hospitals are just looking at it from the point of view that this is going to impact on our activity, we’re going to lose money. Particularly directors in finance and chief executives, this is what they’re thinking. Very few want this [out-of-hospital initiative] to work because they see it as taking patients and money away from them, even though it will improve their performance and outcomes. (S1 P2)

By contrast, the financial logic was rarely referenced at all in the accounts of nurses, an observation encapsulated in the comment of one of the nurses in the second phase:

I’m a nurse, I don’t do money, I just spend it. (S2 P9)

It was further suggested that clinicians in secondary care fail to engage with this logic:

[With hospital consultants] the finances, in fairness, I don’t think comes into it at all ... it’s a quality issue, trying to align a person’s preferred place of care to what we actually achieve ... in secondary care the clinicians don’t tend to think of the finances at all. (S1 P2)

This suggests that financial logics might not become situated in the immediate context of healthcare professional-patient interactions. However, this is not to say that finance did not
exert a more general influence upon collective decisions about where and how best to treat patients nearing the end of life:

The financial pressures are the bed pressures ... and the length of stay of these patients ... I think the financial pressure doesn’t necessarily lead us to give bad quality care to end-of-life patients ... but they are occupying a bed. (S2 P12)

The financial logic as a driver of decision-making was emphasised clearly when referring to the private sector – in the case of end-of-life care this was represented by care homes:

A lot of it is driven by money to be blunt ... because they’re private organisations. They are driven by: we’ve got an empty bed, we need to fill it, and sometimes they don’t think of the consequences of filling that bed ... they go and do a pre-assessment visit, but they don’t get all the information that they should. They don’t think, well, have I got equipment ... it almost becomes a rush. (S2 P1)

Nevertheless, even within the publicly funded system, there was recognition that the perceived lack of money available, and the manner in which money was understood to move among commissioning and contracting systems, did limit what could be achieved:

I think that finance will always be at the forefront of any healthcare setting ... we don’t finance patients in an end-of-life care bed. (S2 P11)

**Logic of patient choice**

As already noted, the logic of patient choice has become a central feature of healthcare policy and the moral value of patient choice is typically juxtaposed against a previous era where clinicians’ judgement was sacrosanct. Hence, patient empowerment was articulated in our findings as important in itself and often supported by emotive arguments that there was ‘only one chance’ to get this right in this context. However, discussions of patient choice quickly surfaced the practical challenges of identifying and accommodating the preferences of patients at the end of life, given that these may not be articulated, communicated, agreed upon and could change at short notice. The following excerpts also draw attention to the key role which families play:

It depends when you’re asking them. It depends at what point in their disease trajectory you’re asking them, because it will change ... it’ll change as the disease progresses and their treatments become less effective and they start to deteriorate. So it’s a constant process really, and I think it’s working very closely with their families. (S2 P11)

The patients are drowsy, unwell and it would be ... difficult for them to tell us ... a lot of the times ... we are guided by the family as to what they wanted. (S2 P12)

There were also practical barriers to meeting patient’s wishes, particularly as achieving a timely discharge from hospital required support to be in place in the community. This, as well as resource shortage, was something referenced much more in the second phase of data collection:

It may be that one area’s got a community palliative team that works 7 days; another one hasn’t. So depending on what that patient’s needs are it may be more difficult to facilitate a discharge for them. Availability of equipment can sometimes vary ... a little bit around the expectations of the family ... the good conversations beforehand [need] to be clear about the actual support that is available in the community. (S2 P8)
In referring to ‘good conversations’ between providers and recipients of end-of-life care, this quote hints at the negotiated status of patient (and/or family) choices.

One of the ways in which the political drives towards choice-based end-of-life care was articulated was in the emphasis being placed upon earlier intervention and support:

R1: patients will say now this is where I want to spend my last days of life or please, I want to go home now.
R2: So they push for home, don’t they, more earlier I think. (S1 FG2)

In practical terms, this could potentially enrol more professionals into the need to conduct what were widely acknowledged to be ‘difficult’ conversations, as well as requiring documentation associated with ACP, and various incentive schemes:

I think quite a lot of patients do have a preference to be at home when they die. I think we are increasingly being asked to ask patients at quite an early stage where they want to die . . . the paperwork and the planning, the DNAR [Do Not Attempt Resuscitation] forms and things like that . . . we formalise that probably at an earlier stage. (S1 P3)

The shift towards earlier planning and managing of death demands difficult conversations and difficult choices of both staff and patients. Importantly, here, the precise nature of patient choice was shaped through interactions with healthcare professionals and others whose role was not just to provide information, but also to advise. Informed choice relied upon a clear articulation of the options available and their implications. Active informing could reassure and encourage a patient to make a particular choice:

We’re eliminating some of the fear they have . . . When you talk to patients . . . about where would you want to die, most will say home, but then they’d be scared of saying a home. But then if you can say ‘look, I will be around whenever I can, I’ll always answer your phone call and, guess what, I’ve got a great hospice at home team who can help you with the symptom control. Because we can offer them that kind of three-way thing . . . It’s that confidence. (S1 P5)

The implicit tension here between patient and professional could become more emphatic when perspectives diverged:

I’ve had one recently completely and utterly refused to have a DNAR. Completely and utterly refused any input from anybody . . . It’s unrealistic of the patient because it was totally appropriate what we were trying to do but if they won’t entertain it you’ve no chance . . . You’re hoping that they’re all going to be receptive to the conversations and they’re not always. (S1 FG1)

There was plentiful evidence of patient choice being curtailed by the logic of finance, particularly in the hospital setting, where it was not only an overly interventionist approach that was seen as preventing a ‘good death’ but also the lack of dedicated (and financed) provision for end-of-life care. Lamenting the loss of palliative care beds within the hospital to beds for delayed discharged patients, one senior sister felt that she did not have much to offer patients by way of choice:

I feel we don’t have much choice for them, if I’m being honest . . . It’s the infrastructure . . . we don’t even have an extra room for relatives for that special moment where we can put our end-of-life patient in a special room with their family so they’ve got dignity there . . . I can’t even accommodate that . . . I think the problem is you’ve got other things take over.

© 2020 The Authors. Sociology of Health & Illness published by John Wiley & Sons Ltd on behalf of Foundation for SHIL (SHIL)
So they’d rather have a ward with a dementia unit for dementia patients ... I don’t think end-of-life is seen as big on the agenda. (S2 P4)

Further emphasising this, several participants pointed out how practicalities often shaped the articulation of choices about preferred place of death:

Patients’ choice is always the most important thing in the world ... But there are a few things that we can do and a few things that we can’t. So coming to the point that the patient wants to die at home, but you can see that the patient is going to die in the next few hours. Then of course the family will be insistent. But then communication is the key, so you have to tell them that the last thing you want is for the person to die in the ambulance ... so patients’ wishes are definitely important, but they need to know the things that we can achieve and the things that we can’t. (S2 P12)

Here it became clearer that patients required support but also guidance in what might suit their particular situation (in terms of diagnosis, state of health, level of carer support, etc.), and this professional role in informing, reassuring and shaping patient preferences reframes what is meant by ‘patient choice’. This was sometimes articulated as achieving consensus, which could be broken down into two kinds – the first, between the different professionals involved:

It’s having confidence in the team on the ward that actually we do know what we’re talking about and everyone is singing from the same hymn sheet ... not one’s saying this and one’s saying that. (S2 P3)

The second, between professionals, patients and their families:

We work very hard to get patients on the same page that we’re on ... A lot of the work our doctors and nurses do on the ward is trying to get people in the same place so that they have an understanding of what’s happening to them now. (S2 P2)

As the last quote suggests, decision-making was something that emerged out of ‘work’ that was put into fusing patient wishes with professional perspectives about what was realistic and advisable. In this way, patient choice in practice was significantly influenced by the third and final logic of professional authority.

**Logic of professional authority**

The broad principle underpinning this logic is that informed and experienced healthcare professionals should be empowered to make the decisions which they feel are appropriate for particular patients in particular situations. This reflects a deeply embedded discourse within healthcare systems which have historically developed and been organised around clinical practice and associated professional interests. While this logic has been challenged in recent years by the emergence of both managerial and patient interests, research has demonstrated the influence it continues to assert within healthcare organisations (Currie and Suhomlinova 2006, Noordegraaf 2011).

In practice, however, this logic was fragmented owing to the multiplicity of professional groups, which operated across different domains and levels of care practice. One of the most explicitly cited examples of this was in the need for hospital and community services to work together, despite the lack of knowledge about the latter in the former:

There’s huge chunks of that very large hospital that still don’t know about us as community [services], even though we are employed by them. (S2 P1)
Coordination is missing when it comes to end-of-life care facilitator she regularly reviews the individualised care plans, and we have link nurse meetings. But although we have made progress there needs to be more progress with our medics. (S2 P4)

In light of the widespread belief that failures in care were a consequence of poor coordination, it was broadly agreed that more coordination was needed the question then became ‘who would be best to lead this coordinated system?’ This produced a range of responses, with groups either articulating why they were particularly well placed to be the key source of professional decision-making here or pointing to their difficulties in acting when faced with another group who asserted their professional authority.

I think it’s got to be the acute complex discharge teams, working collaboratively with the community general district nursing teams, Macmillan teams, AHP teams, dietetic teams. It’s about bridging those gaps and having that collaboration between whatever the patients’ needs are on discharge there’s specialty there to actually do it. But there’s that one point of contact that everything goes through. (S2 P11)

If someone is in the community, I suppose you’d start with your GP maybe the district nurses, maybe a specialist nurse depending on the person’s condition an Admiral nurse maybe or a heart failure nurse, depending on what their illness is once they’re in the hospice we have a multidisciplinary team. (S2 P6)

I think that it is best coming from the consultant looking after the patient I think it would be more receptive to the family this is the consultant responsible looking after my loved one and they have made the decision, so I should abide by it. If it starts off from a junior member of the medical as well as the nursing team, it can very well go the wrong way and then instead of them appreciating that of course they’re approaching end of life, they might take it the wrong way, that you are withholding care unnecessarily. (S2 P12)

Interestingly, for some respondents, the problem of professional authority, and its institutionalisation within acute care, might potentially be resolved by the creation of new specialist roles:

I don’t think medical teams are confident to make that decision When they hit ED it becomes medical then and they want to treat, treat, treat. It’s unfortunate we don’t have a specialist person to say well, actually, put a stop to that. (S2 P4)

As already noted, the problem with the hospital as a setting for end-of-life care was widely cited. In part this reflected concerns with any supposition that the end of life was a medical condition that required ‘treatment’. This was seen as both a practical problem of how things routinely ‘get done’ once someone is in hospital; and a differently embedded problem related to the broader (medicalised) social taboo of death. The following two quotes illuminate each side of this problem:

People who are at end of life, when they come in hospital, you’re taking bloods, you’re doing the regular tests, there are going to be abnormalities. The more that you do, the more it is that you find. You’ve got to treat them then, you see We do test after test after tests. It increases length of stay, and within a few days, oh, the end of life. But that could have all been avoided if that decision was made earlier or they followed the decision that was already there in the community. (S2 P4)

We’re not right at all, we’re so wrong even at a fundamental level, that we don’t address it. It’s not an issue, never mind coordination and commissioning and all that. On a basic
everyday issue, nurses and clinicians, we don’t do it, we just don’t do death, we don’t do death and dying. (S2 P9)

At the same time, it was recognised by some participants that the manner in which hospitals are measured and held to account could reinforce the professional taboo – for example, by taking hospital mortality rates as a measure of quality (or failure):

It’s that taboo thing . . . it’s the old-fashioned thoughts, we can’t let this patient die because it will look like we’ve failed them and the system . . . we can’t let that patient die. I’m not going to let that patient die, and then you lose all that dying with dignity, respect, that all goes out of the window. (S2 P11)

Defaulting to intervention is broadly out-of-step with the ‘good death’ as articulated in policy, which suggests hospitals must be seen as the least-preferred locus of care. More in keeping is the argument that general practitioners should perceive care of their patients at the end to life be their duty. At the same time, the dominance of the doctor, whether in primary or acute care, was challenged by other voices, drawing on a different professional logic based around claims of proximity and personal relationships;

Why should it be a doctor that comes along who doesn’t know that patient and who’s never met them? What about the nursing assistant, the housekeeper, the cleaner that cleans under the bed, the student nurse that spends her 15-week management placement and she’s been allocated a patient; she’s your best person. She’s got this excellent therapeutic relationship. (S1 FG2)

Our doctors, of course, will think they know what’s best for the patient in terms of treatments and symptom management. But they will be the first to admit that they don’t know what’s going on in the patient’s head. They don’t know how it feels to be that patient so they’re always very respecting of patient decisions, but they are very clear that they want to give the patient enough information for them to make an informed decision about the treatment and care choices. (S2 P2)

Across various groups, then, we see the assertion of the professional discourse – informed by knowledge, expertise and with the patient interests apparently ‘at heart’. The resolution of this professional contest relied not only upon argumentation between abstract logics but related more directly to the kinds of boundaries that persist in healthcare and social care settings, and the embedded power relations which structure interactions across these boundaries.

The accounts reflected and reproduced a clear and largely uncontested hierarchy between professional groups; from hospital consultants, to GPs, to district nurses, to social care and finally to care homes. This presumed chain of authority, with hospital consultants at the apex, was routinely referred to:

We’ve got to get out there so that GPs know us and know we’re there, because, for whatever reason, we are still consultants who are special, and we’re put on this kind of pedestal which we shouldn’t be on by patients, but also by GPs to a certain extent. (S1 P2)

At the other extreme, the perceptions of powerlessness through the system, and the implicit disregard for other knowledge and expertise, could be emphatically expressed:

The [nurse] EOL Facilitator is extremely useful, because what do we know? We’re only a care home. She’s seen as the expert in this field, she’s respected in her view. Whereas, maybe, we’re not. (S1 P4)
Crucially, these hierarchies represented the terrain across which the playing out of different logics occurred. The struggle between logics as embodied by different professional groups was conveyed most clearly in the accounts of the nurses. Take, for instance, a reported discussion over the abolition of the LCP between a palliative care nurse and a GP:

I’ve had a GP saying to me ‘are they getting rid of that DNAR as well?’ I said no. He says ‘well, I don’t believe in it’. He said ‘I go into a nursing home and they ask me for it. Use your common sense, the person’s dying, you don’t need one of them’. I said but ‘yes, they do’. But he just wouldn’t listen to me. He says ‘well, I’m not doing them’. And I said ‘well, I think you’re doing an injustice then’ to that . . . but they don’t care. (S1 FG2)

On the one hand, this exchange serves to articulate differing professional logics regarding management and decision-making in end-of-life care. The reference to ‘using common sense’ reflects the professional discretion demanded by and accorded to elite professions — requiring a personal acceptance of authority which is significantly more challenging and risky to a nurse than a GP. On the other hand, the nurse’s response drew on the legitimacy accrued by being close to the patient and having a better grasp of the patient’s interest (and a moral concern about ‘injustice’ to the patient). The sense of moral outrage, given additional intensity by perceptions of professional disrespect, was tangible here — the nurses in question appropriating the question of the patient’s right to choose as their particular and exclusive concern.

At the same time, these logics were not implacable positions, and in practice examples were found of individuals, particularly nurses, who managed to influence more powerful professionals, in particular GPs, so as to ensure their logic informed decisions and action:

That’s about six GPs, and they’re quite — not aggressive — ‘vocal’. It’s took about 12 months to get where they’re actually listening to what we’ve got to say really. We attend the meetings . . . they said this patient was deteriorating but . . . there was no plan of action. So I said perhaps if you prioritised your patients it might be a bit easier for you. ‘Oh yeah, that’s a good idea’. You can’t go in all guns blazing. But they are listening now. (S1 FG3)

Another case, this time in the community, was the offer of assistance by a hospice at home service which was received as criticism by those already caring for a patient:

We received a lot of resistance from the district nursing team at that time . . . I think they felt a little bit criticised . . . We fought through that and I have to give my nurses and the healthcare assistants who went out undertaking these hospice-at-home visits a lot of credit for just battling through . . . It probably took us between 18 months and 2 years before we were fully accepted and integrated into the community. Now we have district nurses making referrals for our community service. (S2 P2)

In these cases, prolonged, relational work across teams was necessary to help reconcile conflicting positions.

Discussion

Our paper presents an exploration of the manner in which different practitioners attempt to interpret and respond to the need for patient choice, in the context of the contested and conflicting professional and organisational logics shaping the delivery of end-of-life care. We have presented our empirical material according to three broad logics; financial, patient choice and professional. In light of the literature on end-of-life care, and other research into logics in health care, it is perhaps unsurprising that we find examples of a market logic (articulated
through ‘patient choice’), a financial logic (framed in terms of ‘efficiency’ and ‘cost-savings’) and also professional/clinical logics (of which the traditional biomedical logic associated with hospital doctors is just one example and the focus of substantial struggle). In addition, these bear broad resemblance to some more widely accepted frameworks common in research on health care – between market, bureaucracy and profession (Friedson 2001). Our data demonstrate the close inter-relation of these logics. Hence, financial related to professional, including GPs as small business owners and commissioners, but also in the entanglement of financial and professional logics in acute medicine – both seen as unfavourably related to ‘good’ end-of-life care. Patient choice was deployed by particular professional groups especially those perceiving themselves to be closest to the patient, often nurses or care home staff. However, this choice was not only supported but also informed and even directed by those closest to the patient, affording the nurse greater influence on end-of-life care where this dominates. Finally, the professional logic is most contested, and most associated with issues of ‘ownership’ and hierarchy – particularly when these two factors were at odds (e.g. district nurses vs. GPs). This demonstrates greater complexity at play in the hierarchical relationships of healthcare practitioners than is conventionally understood as the ‘doctor-nurse game’ where physicians are considered the ‘dominant profession’ (Forbes et al. 2018, Pritchard 2017: 34). We show how these traditional perceptions are openly problematised, resisted and in some cases circumvented by nurses and other ‘non-dominant professions’, with material effects upon decision-making and patient choice (Pritchard 2017).

Each of the three logics was deployed by different professional groups across organisational settings in different ways, to pursue different agendas, and each implied a different emphasis in terms of what ‘good’ care should seek to achieve. In turn, each constellation of logics shaped patient choice as to what end-of-life care they receive. Often, the logics of finance and professional authority could override the patient choice logic, in sculpting and limiting the choices available to the patient. This is therefore not only a question of abstract ideas in contestation but also about professional jurisdiction and dominance and, therefore, about the impact of power relations in this field.

Goodrick and Reay suggest three ways in which the existence of multiple institutional logics might play out; (i) Among existing logics, one is dominant and guides behaviour; (ii) Multiple logics battle with each other for dominance, and (iii) Multiple logics differentially affect different actors, geographical communities, or organisations’. (Goodrick and Reay 2011). In this study, what is witnessed is the interplay or battle between all of these. More importantly, and particularly in the case of the professional logic, this is structured by hierarchical relations in the field of end-of-life care between professional (rather than organisational) groups, yet there is also evidence from our findings, that the professional logic might be ‘hybridised’ (Hodgson et al. 2015) according to the organisational commitments held by individuals in different parts of the system. For example, across different logics there was a perceived correspondence between an interventionist/medical stance in hospitals which simultaneously reproduced both a financial imperative and a social taboo of death. In different parts of the system, it appeared possible to enact alternative forms of professionalism, for example, district nurses could claim ‘ownership’ of patients on the basis of their close and continuing contact with patients, thus articulating a ‘person-centred’ professionalism with which to attempt to meet choice. At the same time, district nurses relied substantially upon bureaucratic processes, such as ACP and DNARs as negotiating devices with more powerful professionals, thus articulating choice as ‘getting things done’ according to what they felt was in the best interests of patients. Different forms of professionalism therefore could afford different understandings and realisations of choice, with nurses drawing strategically on multiple logics to perform an embattled professional script of ownership.
Conclusion

Our paper has illuminated complex and ambiguous ethical questions relevant to the attempt to deliver choice-led end-of-life care. How these questions are interpreted and acted upon by individual practitioners is shaped by organisational and professional logics, and three in particular: financial, patient choice and professional authority, which reflect meta-logics of finance, market and profession. These logics are interconnected in practice and the interplay of these logics is complex, variegated and unpredictable in the extent to which they might limit or afford particular actions by particular individuals. The dominant philosophy in end-of-life care, embedded in policy and practice, seeks to privilege patient choice and encourage what is seen as more cost effective, out-of-hospital activity. However, analysing the logics at play in this field shows how patient choice is structured by the actions of different health and care professionals, and that hierarchies of authority within health and care influence these actions. This is not a predictable situation of medical authority superseding nonmedical, or doctor versus nurse, however – these dynamics are present, but influence is also mobilised by being familiar with patients and their families, by the physical location of the patient within different organisations (care home, hospital, etc.) and by the alignment of professional values with current conceptions of a ‘good death’, that is, at home or out of hospital, avoiding unnecessary intervention, lower cost and (at the same time) in line with the wishes of the patient him/herself.

The values that practitioners bring and are able to enact within end-of-life care therefore might have a significant impact on outcomes. As Candrian (2014: 65) observes, ‘the discourses surrounding end-of-life care are filled with conflict and ambiguity. When there is conflict and ambiguity, there is struggle over what to value’. Developing this further, our paper demonstrates a recursive relationship between logics and values, wherein values are nested within particular logics, which in turn shape the enaction of particular values.

We would like to signal three contributions made by this paper: First, within the field of end-of-life care we have shown how different interests seek to harness ‘patient choice’, and that consequently what stands for patient choice requires scrutiny. Second, we show how professional hierarchy is supported and contested in particular settings and how a new discourse (here, the contemporary ideal of the ‘good death’) offers ways in which power hierarchies can be challenged. Lastly, we have demonstrated the value of engaging with institutional logics in order to unpick complex situations where moral and professional questions are in play. Through describing and clarifying these logics, we have attempted to show how and where they are articulated, how they become embroiled in larger games, such as battles for professional dominance and financial survival, and what the consequences of this are for the situated and emergent manner in which ‘good’ end-of-life care is performed.

Address for correspondence: Simon Bailey, School of Social Policy, Sociology and Social Research, George Allen Wing, University of Kent, Canterbury CT2 7NZ, UK.
E-mail: s.j.c.bailey@kent.ac.uk

Author contributions

Simon Bailey: Conceptualization (equal); formal analysis (equal); funding acquisition (equal); investigation (equal); methodology (equal); writing-original draft (lead); writing-review & editing (equal). Damian Hodgson: Conceptualization (equal); formal analysis (equal); funding acquisition (equal); investigation (equal); methodology (equal); writing-original draft (lead);
writing-review & editing (equal). **Sarah-Jane Lennie:** Formal analysis (equal); investigation (equal); writing-review & editing (equal). **Mike Bresnen:** Conceptualization (equal); formal analysis (equal); funding acquisition (equal); investigation (equal); methodology (equal); writing-original draft (supporting); writing-review & editing (equal). **Paula Hyde:** Conceptualization (equal); formal analysis (equal); funding acquisition (equal); investigation (equal); methodology (equal); writing-original draft (supporting); writing-review & editing (equal).

**Data availability statement**

Data from this article is qualitative and therefore cannot be made publicly available.

**References**


© 2020 The Authors. *Sociology of Health & Illness* published by John Wiley & Sons Ltd on behalf of Foundation for SHIL (SHIL)


© 2020 The Authors. *Sociology of Health & Illness* published by John Wiley & Sons Ltd on behalf of Foundation for SHIL (SHIL)


