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Planning for an (un)certain future: choice within English end-of-life care

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Abstract

Neoliberal policies are shaping the healthcare landscape by emphasising individual choice. End-of-life care is a case in point as patient choice, through advance care planning, is a key conceptual framework for motivating service development and provision. Based on qualitative ethnographic research in England, this paper describes what choice is and how it is enacted in the context of end-of-life care. Within policy, choice represents individual autonomy and is a goal to strive towards. In order to enable choice, healthcare professionals are to openly discuss dying with patients and in turn, patients are expected to express their preferences. However, by focusing on two case studies, the paper demonstrates how people struggle to articulate choice in these ways and the preferences expressed represent the complex contexts in which care is performed. Although death is certain, the possibility of control alluded to by choice rhetoric is not realised in practice.

Introduction

The landscape of healthcare is changing with an increased emphasis on individual choice. End-of-life care, as practiced in places like the UK, USA and Australia, is a case in point as patient choice – within a wider set of neoliberal policies – is a key conceptual framework for motivating service development and provision. This paper addresses what choice in this context is and how people are experiencing 'choice'. In turn, it describes the ways in which people engage with the idea of making decisions about end-of-life care. By focusing on qualitative ethnographic research from England, contrasting healthcare policy rhetoric with two patient case studies, this paper argues that choice discourse is shaping the way death is to be managed through choice. There is now a responsibility to articulate and achieve patient preferences at a time when other factors– such as the timing and messiness of death – remain outside of perceived normal parameters of control.

End-of-life care in England aims to provide high quality care in the last year of life, primarily supplied through the National Health Service (NHS) and wider welfare state regimes. The NHS was formed in the late 1940s to provide a cradle-to-grave medical service that was free at the point of need (Rivett, 1998). The principle of State supported healthcare has remained at its core although there has been an increased

amount of marketization and decentralisation within the NHS since the 1980s.

Reshaping welfare-based regimes rather than abolishing them is theorised as a form of

neoliberal governmentality (Hartman, 2005), where a person's claim and access to care

form a new kind of biological citizenship (Ong and Collier, 2005). In the context of end-

of-life care, this is evident in the emphasis on patient choice.

A fundamental tenet of neoliberal policies is the ability and necessity for an individual

to make choices (McGregor, 2001), assuming that they will favour themselves and

promote their own lives. Since the 1990s, due to 'tremendous popular and political

appeal' (Appleby et al., 2003: vii) there has been an increased emphasis on

individualistic patient autonomy within the NHS. Patients and healthcare professionals

are to work collaboratively towards deciding a patient's course of treatment, and

service provision is to iteratively change in response to population and patient

preferences and needs (Appleby et al., 2003). In the policy discourse, having choice is

equated with improved patient experience (DH, 2003). This shift reflects the 'subtle

and cumulative manner' in which consumerism and neoliberal values have become

part of healthcare policy (Greener, 2009:309). In this new model, patients are 'users' of

the NHS rather than passive receipts of care, empowered through their choice (Veitch,

2010), and in turn healthcare professionals and policy-makers shape the ways in which

services are accessed and implemented.

There have been many critiques of neoliberal healthcare politics (e.g. Scott-Samuel et al., 2013) and the notion of patient choice (Bryant et al., 2007). Yet, the way neoliberal values are adopted varies internationally; understanding local articulations of these values helps describe the limits of neoliberalism as a totalizing force (Kingfisher and Maskovsky, 2008). Rather than presenting a critique based on the principles of these policies, this paper offers ethnographic insight into how they are being constructed, adopted, and enacted – or even resisted – in specific ways. In particular, this research is based on how 'choice' is mobilised in English end-of-life care policy, and how people who may be the subject of end-of-life care policy perceive, discuss, and enact 'choice'. This paper argues that within policy discourses, choice is an ideal and is treated as a goal. When it comes to elucidating choice and talking to patients about their preferences, 'choice' reflects an imperfect process that does not adequately capture their experiences as they come to the end of their lives. Ultimately, the experiences of considering choices at the end of life do not neatly fit into the idealistic ambitions of end-of-life care policy.

Background and methods

End-of-life care is a relatively new domain of healthcare practice, growing from the hospice movement and specialist palliative care (Seymour, 2012). The Department of

Health for England and Wales released the first national end-of-life care policy in 2008 – the End of Life Care Strategy (DH, 2008) – and several countries have since followed suit or are in the process of devising policies (e.g. Macaden 2011; Department of Health, 2010). The strategy calls on healthcare professionals to identify patients that may be in their last year of life and to plan with these patients their future care and death, a process known as advance care planning (ACP). It is hoped that through care planning hospital admissions at the end of life can be avoided, thereby reducing costs to the NHS (Gott et al., 2013). Under this framework, death is not something that 'just happens' to people, but something that can be anticipated and planned for.

Patients are expected to want to organise circumstances around their death, although assisted dying is illegal, building on a small practice of writing living wills or advance directives, appointing power of attorneys, and funeral planning. This kind of anticipatory decision making can be considered a neoliberal cultural practice imported from North America (Thomas et al., 2008) and it is understood as supporting a person's dignity towards the end of life by affording them control over their death (Tang and Chen, 2012). Importantly, the logic is that incorporating patient choice through advance care planning enables patients to have a 'good death'.

This paper is based on a subsection of data from a larger ethnographic study of English end-of-life care conducted between 2010 and 2012. The purpose of the study was to explore how the concepts embodied in the policy discourse, especially 'choice', are translated into healthcare practice and how people who may be the subject of end-of-life care policy perceive, discuss, and enact 'choice' and whether this reflects their experiences of the everyday as they live with long-term and/or terminal illness (Borgstrom, 2014). The study had approval from the local National Research Ethics Service committee and all participants consented to the interviews and observations. It involved analysis of policy documents related to end-of-life care, as well as over 50 hours of observations of policy-related events, 250 hours of participant-observation in clinical settings and support groups, and over 100 semi-structured interviews with policy makers, healthcare professionals, patients and their families/carers. As part of a longitudinal study, 10 individuals/couples recruited through support groups or hospice centres were interviewed multiple times over 14 months. Fieldnotes were written from observations and interviews; analysis focused on how people discussed and performed choice and advance care planning, how death was defined and managed, and how people made meaning of their lives.

This paper deliberately parallels policy rhetoric of choice with two patients' experiences of being confronted to consider their end-of-life care preferences. This is

done to emphasise the various ways in which choice is perceived and enacted, or even resisted, thereby demonstrating the malleability and agency of the concept as a moral construct. The first section – choice as a goal and solution – describes the way language is used to present choice in end-of-life care as a way to reform the care of the dying through managed palliative care. My argument draws on statements made in policy documents, such as the End of Life Care Strategy (DH, 2008), and the related scientific and academic literature that is used to support policy ambitions. In these documents, the concept of choice is represented in the allied language of preference, decision-making, and advance care planning. These studies were often cited in events where policy-makers promoted the Strategy to local healthcare commissioners and professionals. This section also highlights the organisational changes – such as how deaths are audited – that support the discourse of choice in practice.

The second section focuses on the experiences and accounts of two men – Chris and Oscar (pseudonyms), with whom I met regularly during the course of the study and could follow as their lives unfolded. Fieldnotes from our visits and interview transcripts were analysed for how they described and made sense of planning for the future, which were then categorised under the themes described in the second section. Both had deteriorating health conditions and were considered to be 'end-of-life care patients', in so far as healthcare professionals suggested that their prognosis could be

12 months or less (although both lived on for years after the start of the study); in this sense, they are prime candidates for advance care planning. However, neither of them actively sought to make these plans and both found it a difficult process, as described later. Whilst I met with over 40 'patients' as part of the larger ethnography, both Chris and Oscar openly reflected and were articulate on the issues of choice. In this sense they were unusual in their willingness and ability to describe why they did not 'make plans' but their reticence was shared with many more people in this study and other research (Boyd and Murray, 2014). Whilst these accounts are not broadly representative, as both Chris and Oscar openly discussed dying, both men were able to give voice to the complexity of planning ahead in the context of end-of-life care, which helps problematise the policy rhetoric.

Chris was in his mid-fifties, recently and reluctantly retired due to his diagnosis of aggressive cancer, for which he received intensive treatment despite an unknown, and potentially short-term, prognosis. No longer employed, Chris and his family defaulted on their mortgage and had to be moved into social housing, which in itself presented an ongoing battle. I initially met him through the hospice day-therapy service where I did participant-observation, and was able to discuss his care with the staff there. Chris and I met for informal interviews 15 times over the course of a year, with him often

choosing to frequent places that were involved in his care, and we regularly exchanged emails about his creative writing concerning his condition.

Oscar was in his mid-sixties and lived with his wife Pamela who was an ex-nurse and his main carer. Like Chris, Oscar retired early due to deteriorating health; in his case, caused by a degenerative neurological condition which required numerous hospital visits for tests in the 'early years' and a slow loss of mobility and motor-control. I visited Oscar and Pamela in their home approximately once a month for 14 months for long semi-structured interviews – or 'discussions' as Oscar called them. During this time, Oscar was very reflective and would steer the conversation on to topics that he was passionate about. He openly admitted that he spent time thinking about what we should discuss in between visits, and our conversations also covered both his and Pamela's fluctuating health statuses, including Oscar's more recent diagnosis of cancer. During this time, I was also able to observe how Oscar interacted with nurses at the same hospice-day therapy centre that Chris attended, and we used his visits as a prompt for some of our discussions.

The first section below discusses how choice is framed as a goal and solution within end-of-life care policy. In particular, it outlines the emphasis within policy to promote more 'home deaths' through patient choice. In contrast, the snippets from my

discussions and observations with Chris and Oscar demonstrate how 'choice' was an imperfect prospect for them, even though they were theoretically (from the policy perspective) in a position to be making these choices. This section outlines how choice was discussed and the contextual nature of the decision-making that was involved. Overall, the comparison between policy rhetoric and people's lived experiences is used to comment on the role of choice in (English) end-of-life care.

Choice as a goal and solution

> *'There is a solution. Over half a million people die each year, yet 70% have not discussed their own end of life wishes with their partner, family, friends or health or social care professionals.'* - Excerpt from Dying-Doing It Better booklet from the National Council for Palliative Care and Dying Matters (2012:4)

As illustrated in the quote above, within English end-of-life care policy, 'choice' is constructed as a solution to 'the problem' of death. This problem, as it is presented, is one of increasing rate and need that will outstrip the hospital and hospice resources (NCPC & DM 2011). By 2030 it is expected that 530,000 will die each year (Richards, 2008), many of them having long-term and multiple illnesses towards the end of life, including an increase in dementia, which can impact decision-making in the present

(Fellows, 1998). The increasing rate of deaths within the country due to demographic changes is projected to put a strain on the institutional provision of healthcare, particularly within hospitals which is where most people have died within the UK over the last few decades (Gao et al., 2013). Moreover, death is commonly portrayed and experienced as a failure within medicine (Bishop, 2011) and doctors may be reluctant to discuss terminal prognoses with patients and their families (Barclay et al., 2011). Within the last decade, there have been several public discussions within the popular media about how dying people are cared for, with a perception that the National Health Service fails to provide people with dignity and respect as they die (Alghrani et al., 2011). Not only then is death itself seen as a failure within medical practice, but also medical professionals are portrayed as failing to adequately care for the dying.

The primary exception to this perception is specialist palliative care, for which provision is inequitable across localities and disease groups (DH 2008). Practitioners of palliative care pride themselves on their philosophy of holistic care, whereby the social, psychological, spiritual and physical elements of the patient are taken into consideration and patients are frequently involved in the treatment and care decisions that affect them (Latimer, 1991). To improve the quality of care provided at the end of life, the national End-of-Life Care Strategy (DH, 2008) sought to rollout tools and methods commonly used within palliative care to all patients who were identified as

being in the last year of their life. Most of these involve the process of Advance Care Planning (ACP), whereby people state preferences for the level and kind of treatment they would like to receive in the future should their health worsen. These 'choices' are to be shared between healthcare professionals to ensure care is provided to meet patient preferences as much as possible. From this policy perspective, ascertaining and acting upon patient preferences therefore represented a solution to providing dignity and care as more people die.

Home death as a specific goal

On one level, offering patients choice is the overarching goal of English end-of-life care policy. However, there is a specific kind of choice that policy-makers promoted. This is the ability for people to die in their preferred place, typically their home, a trope that is repeated several times within the Strategy.

Policy documents reference reports that most people prefer to die at home (Higginson, 2003) although other studies suggest this choice can change over time and with disease progression (Ditto et al., 2006). Moreover, the policy definition of a 'good death' is one that occurs in a place familiar to the person, alluding to their home (DH, 2008:9). Consequently, a significant amount of the funding associated with the strategy was directed at improving care in the community and training up generalists

(Richards, 2008). For example, the Strategy endorsed the Delivering Choice programme, which in practice focused on providing care to people in their homes and discharging patients from hospital to die at home, in accordance with their wishes. Delivering choice then is about providing the ability to die at home, or in other words, to create a home death. Choosing, and being able, to die at home are therefore constructed as the same goal within the policy discourse.

The measurement of this kind of choice further illustrates the goal-like quality of the concept within policy. There are various metrics linked to advance care planning and place of death as a way of assessing the quality of the dying experience and of the death (NICE, 2011). General practitioners, for example, are encouraged to keep a record of how many patients they had discussed end-of-life care issues with, how many completed paperwork stating their wishes, and the preferred place of care and/or death (NEOLCIN, 2013). After 2008, these figures were annually audited locally and nationally by the NHS and Office of National Statistics to document the effect of increasing patient choice. The anticipated trend was to observe an increase in the amount of 'choice' happening as a result of the national strategy. Soon this included comparing a patient's preferred place of death with their actual place of death (Gomes et al., 2011) as a way of monitoring the healthcare system's ability to deliver on patient choice at the end of life. Although hospitals continue to be the main site where active

dying and death occur, and may be the preference of the patient and their family

(Gerrard et al., 2011), the main focus within policy circles is to increase the rate of

home death. The routine auditing of these figures – itself a neoliberal technique of

governance – demonstrates the strategic nature of choice as a motivation for and

marker of care within policy discourse.

Choice continues to be framed as a timely solution for the problem of death within

policy thinking about end-of-life care (Henry et al., 2015). Providing the ability to

choose and facilitating choice are seen as goals within policy as choice is perceived to

embody and represent a 'good death', quality of care, and to some extent, the value of

personhood. Choice, in these various permutations, provides something to strive for.

By alluding to the 'one chance' element of dying and death, ensuring patients have

choice and acting on these preferences is considered an ultimate form of respect and

way of honouring the individual before they die and can no longer express themselves

(e.g Leadership Alliance, 2014). In this context, choice is deemed as a triumph over the

potential for failure and lack of control that death and dying present.

Choice as an imperfect prospect

'How can we plan for the future if we don't know what tomorrow will be like?

We live each day as it comes…' – Oscar commenting on his and Pamela's lack of

documented care plans

Through discussing 'choice' and how Oscar and Chris made plans (or not, as was often

the case), it was evident that these were negotiated processes that often took place in

an imperfect system. In principle, they, and many more people that I interviewed as

part of the larger ethnography, agreed with the idea of expressing preferences about

end-of-life care and that, as much as possible, these wishes should be supported.

However, these same people did not engage with advance care planning, either in the

formal process or the documentation, even if healthcare professionals routinely asked

them. Instead, Oscar and Chris described the ways in which they 'muddled through'

the healthcare system, especially in not knowing who could give them what

information when. This sense of uncertainty affected their ability to plan for their

(certain) deaths. As outlined further below, the main reasons why enacting choice as a

discussion of patient preferences was more complicated than portrayed within the

policy rhetoric is that: dying was not always easy to discuss; expressing decisions was

rarely viewed as a discrete event and preferences could change over time; and, Oscar

and Chris, as well as others in the wider study, did not feel they ultimately had

autonomy or agency. Consequently, thinking about choice as embedded in practices,

rather than just a rhetorical device or political value, demonstrates the complex, and incomplete, ways in which neoliberal policies are being articulated.

Discussing and documenting end-of-life care choices

In my discussions with Chris and Oscar, it was evident how challenging it could be to broach and discuss the topic of death, and the hospice staff confirmed that they also found it difficult. This corresponds with other studies about breaking bad news and talking about death (Barclay and Maher, 2010) and the Dying Matters Coalition (established through the national End of Life Care Strategy) suggests that dying is not regularly openly discussed, or at least not as much as it should be (Seymour, French, et al., 2010). From a policy perspective, discussing dying and death is a pre-requisite for making decisions about place of care, often frankly and euphemistically labelling these 'difficult conversations' (Barclay and Maher, 2010).

Observations of completing the Preferred Priorities of Care Document with Oscar in the hospice demonstrated the delicate dance nurses had to conduct as they attempted to ask about his preferences, without upsetting anyone, and redirecting him to care planning instead of informal conversation. The hospice staff set themselves the goal of documenting a patient's choices within a 12-week period, expecting it to take several attempts to broach the topic and then another few weeks for the patient to think and

talk about their preferences with others. It was not unusual to witness the clinical staff repeatedly discuss care planning with patients over several days.

This is what happened with Oscar, and over several weeks he suggested that he would like to be cared for between home, a care home, and the hospital, depending on how his wife was coping with 'taking care of' him. Due to this, he did not want to write down a 'single preferred place', despite the nurse suggesting this would be best, as he perceived the act of documenting his preference as 'writing it in stone…where it would be final'. The ways in which documented choice were shared between healthcare professionals in hard-copies of patients' notes supports the idea that 'changing one's mind' could be difficult to enforce within the wider support network. The inability to pin down a preference was further complicated for Oscar, as the opening quote of this section illustrates, when the nature of disease and decline was uncertain. The changing nature of disease and care situations, and the time it could take to understand what one's preferences may be in the context of these, therefore were not reflected in the way end-of-life care choice was operationalised within the healthcare system. Moreover, nurses viewed knowing when and how to talk to patients about their end-of-life choices, and ensuring the documents 'required' for care and audit were completed, as a professional balancing act that played concerns about individual patient welfare against the routinized nature of healthcare.

Although both Chris and Oscar had considered what kind of care they would prefer towards the end of their lives, they expressed these as 'private' wishes, reluctant to share them with their family. For example, Chris did not want to share his views with his family as he did 'not want to upset' his wife or adult children. He worried that discussing death (and his inclination to shorten his life) would spoil family-life and the remaining time they had together. Similarly, Oscar was concerned that if he articulated fully what he wanted, it would present a burden for Pamela, who would feel responsible to care for him as he died at home. Therefore, even though they had considered their 'end-of-life choices', they did not necessarily feel these choices were something that could readily be shared, as the sharing of these preferences would (negatively) change the family dynamic. This is not the same as saying that people are in denial about their conditions or that death is a taboo topic (Zimmermann and Rodin, 2004); these findings illustrate the complex context in which end-of-life care choice is situated when it is enacted and the perception of addressing a person's 'dying wishes' in the context of social relationships. Although English end-of-life care policy promotes a 'let's talk about it' attitude, those tasked with confronting end-of-life care choices in practice and near their own deaths found the process of communicating 'choice' complicated.

Perceived lack of individual autonomy and agency

> *'…[Chris was talking about] how he can make people realise they have 'choices' and once they see that, they feel they have options and can be more optimistic about life and go on. I turned this on him and asked if he thinks he has choices and he said no. We sat in silence for a long time after this…'* – notes from an interview with Chris discussing his interactions with his family and other patients in the hospice

As the notes from a discussion with Chris above indicate, people may feel they have limited or no individual autonomy or agency when it comes to death and dying, even if they think others have this agency or that they themselves may have agency at other times in their life. This ranged from perceiving a lack or limited range of choice to distancing oneself from the process of making decisions and the decision made. Individual agency was displaced in these discussions as end-of-life care choices were framed within the healthcare system and were contingent on bodily processes.

The idea that 'death comes to us all' pervaded many of the discussions about the futility of making decisions about the end of life. For Chris, the uncertain prognosis of his condition meant that he felt he had no way of preparing for the future, as he could not imagine what it would be like or how long he had 'to get there'. For example, he was unsure if his condition would improve enough for him to do some voluntary work

that he was interested in, so rather than explore this further he ruled it out as an option (even though he thought other people should be more proactive in their own lives). Similarly, instead of actively planning his end-of-life care, he opted for a fatalistic approach – 'whatever will come, will come'. Whilst this in itself could be viewed as an assertion of autonomy, it does not fit with the policy position of actively engaging with advance care planning.

When patients did talk about making decisions about the future, it was not always something that they viewed as 'mine to make'. For example, when Oscar and I discussed how the hospice staff asked him about his preferences for future care, he felt the 'choices' did not always reflect his 'own personal desires'. We extensively discussed how he had to consider the needs of his wife, with her own health issues, and how their adult children would react to the increasing care he would need to stay at home. When I spoke to him and Pamela, they referred to his end-of-life care preferences as 'our choice' to reflect the shared decision-making process they undertook when it came to his care. In this way, models of individual autonomy and rational decision making do not reflect the way people perceived and projected choice at the end of their lives.

Overall, 'doing choice' represented a number of processes and negotiations that did not always result in the articulation of an individual's preference. Instead, the 'choice' represented the limitations of free will in the context of end-of-life care. Although death may be certain, the uncertainties of how dying unfolds and the caring responsibilities it can require problematizes the 'choice as goal' rhetoric of policy.

Discussion

English end-of-life care policy, as described in the first section, formulates choice as a goal and objectives for healthcare practice and patients to realise. Specific choices can be known through discussions with patients about their personal preferences, for example, where they would like to be cared for and die. These preferences – or choices – are to be documented and shared amongst healthcare professionals. Often, place of death is the main 'choice' addressed in policy discourse and tools used to promote patient choice at the end of life, although this is a rather limited view of what choice can be.

Moreover, the experiences of making these 'choices' often left people feeling that individual choice was not something they had. Instead, what became known as 'patient preference' or 'patient choice' were often ideas forged through processes of negotiation and subject to external concerns. As evident in the previous section, what

became known as 'choice' was not the individual choice that is the goal of policy, but an expression of the entangled relationships patients are part of as they near the end of their life. Having to express choices, whilst envisioned as empowering, often highlighted for people the complicated and conflicting nature of dying and providing end-of-life care. This contested nature of choice makes it a problematic goal, as the ultimate control over death, which is the fundamental element of choice throughout these examples, remains elusive.

These versions of choice correspond with previous commentaries about the role of choice in neoliberal contexts. Neoliberalism is linked to greater individualism (Coburn, 2003) and choice has become a requirement (Giddens, 1991). This research supports Walter's claim that dying in the contemporary neoliberal period is informed by the policy assumption that individuals can be aware of their deaths and liberated through choice (Walter, 1994); indeed, choice has a moral quality of personhood in policy discourse. Yet, research has shown that there is variance in people's desire to be part of end-of-life care decision-making (e.g. Heyland et al., 2003). The empowering role of choice, when choice is a requirement rather than an expression of free-will as the term initially implies, is questionable (Barnes and Prior, 1995; Drought and Koenig, 2002). Whilst this paper has deliberately set up the policy rhetoric against how articulating end-of-life care choices is experienced, both of these can be interpreted as ways in

which the neoliberal value of individual autonomy is being understood in the context
of English end-of-life care.

The way choice is being utilised within policy is reconfiguring services around market
principles. Globally, care is increasingly commodified within market logics of choice
(Green and Lawson, 2011). In turn this is changing the nature of the relationship
between healthcare professionals and patients (Mol, 2008); patients are expected to
take more responsibility for their health and now even their deaths, choosing from a
variety of services and treatment options. A focus on personal choice risks reducing
the personal, and dignified, nature of care by eroding the intimacy of the care
relationship (Owens, 2015), which is supposed to be at the heart of end-of-life care
policy. Moreover, the routinized ways in which advance care planning is done risks
undermining its core values by focusing on documentation rather than the person, as
has happened in hospice care previously (James and Field, 1992). The assumption then
that choice – and activities that involve patient choice – at the end of life equates to
high-quality care is problematic in that it does not address the relational, and often
subtly negotiated, nature of care.

The concept of individual choice, often based on the notion of free-will and rationality,
has been heavily critiqued (e.g. Salecl, 2010). What is denoted as someone's

preferences are influenced by the context of decision-making (Ditto et al., 2006), and studies on advance care planning have shown how setting, relative health status, and relationships affect the preference people express (Seymour et al., 2010). Although it is suggested that advance care planning improves the quality of end-of-life care (Brinkman-Stoppelenburg et al., 2014), it is not clear if it improves the experience of dying; studies on birth planning have shown that planning ahead does not necessarily meaningfully change the experience (Peart, 2004). The practice of advance care planning should not be so readily conflated with the idea of individual autonomy, assuming that they both have the same material and meaningful consequences for people's experiences of dying and death.

Conclusion

In the context of English end-of-life care, choice is imbued with positive moral values; this is similar to how choice operates in many neoliberal policies. It is rhetorically understood as both a standard goal that can be achieved and an attribute of the person. It is deployed as a way to manage the problem of dying, whilst not altering the timing or means of death. Yet, the ways in which choices are made known and acted upon reflect the complex nature of care and situations that people are part of. Even if

people can assert preferences about their end-of-life care when death is ultimately

certain, 'choice' cannot control the uncertain ways in which dying processes unfold.

References

Alghrani A, Brazier M, Farrell A-M, et al. (2011) Healthcare scandals in the NHS: crime and punishment. *Journal of Medical Ethics*, 37(4), 230–232.

Appleby J, Harrison A and Devlin N (2003) *What is the Real Cost of More Patient Choice?* London:Kingsfund.

Barclay S and Maher J (2010) Having the difficult conversations about the end of life. *British Medical Journal*, 341, 653–655.

Barclay S, Momen N, Case-Upton S, et al. (2011) End-of-life care conversations with heart failure patients: a systematic literature review and narrative synthesis. *British Journal of General Practice*, 61(582), e49–62.

Barnes M and Prior D (1995) Spoilt for choice? How consumerism can disempower public service users. *Public Money and Management*, 15(3), 53–58.

Bishop JP (2011) *The Anticipatory Corpse: Medicine, Power, and the Care of the Dying*. Notre Dame, IN: University of Notre Dame Press.

Borgstrom E (2014) Planning for Death? An Ethnographic Study of English End-of-Life Care. Unpublished PhD. Cambridge: University of Cambridge.

Boyd K and Murray SA (2014) Why is talking about dying such a challenge? *British Medical Journal*, 348, g3699.

Brinkman-Stoppelenburg A, Rietjens JA and van de Heide A (2014) The effects of advance care planning on end-of-life care: A systematic review. *Palliative Medicine*, 28(8), 1000–1025.

Bryant LD, Bown N, Bekker H, et al. (2007) The lure of 'patient choice'. *British Journal of General Practice*, 57(543), 822–826.

Coburn D (2003) Globalization, neoliberalism and health. In: Sandbrook R (ed.), *Civilizing Globalization: A Survival guide*, Albany, New York: University of New York Press, pp. 27–38.

Department of Health (2003) *Choice, Responsiveness and Equity in the NHS and Social Care: a National Consultation*. London: HMSO.

Department of Health (2008) *End of Life Care Strategy*. London: HMSO.

Department of Health (2010) Supporting Australians to Live Well at the End of Life: The National Palliative Care Strategy. Commonwealth of Australia.

Ditto PH, Smucker WD, Danks JH, et al. (2006) Context changes choice: A prospective study of the effects of hospitalization on life-sustaining treatment preferences. *Medical Decision Making*, 26(4), 313–322.

Drought TS and Koenig BA (2002) 'Choice' in end-of-life decision making: Researching fact or fiction? *The Gerontologist*, 42(Supplement 3), 114–128.

Dying Matters (2011) *Dying - Doing It Better*. London.

Fellows L (1998) Competency and consent in dementia. *Journal of the American Geriatrics Society*, 46(7), 922–926.

Gao W, Ho YK, Verne J, et al. (2013) Changing patterns in place of cancer death in England: A population-based study. *PLOS Medicine*, 10(3), e1001410 .

Gerrard R, Campbell J, Minton O, et al. (2011) Achieving the preferred place of care for hospitalized patients at the end of life. *Palliative Medicine2*, 25(4), 333–336.

Giddens A (1991) *Modernity and Self-Identity: Self and Society in the Late Modern Age*. Stanford: Stanford University Press.

Gomes B, Calanzani N and Higginson IJ (2011) *Local Preferences and Place of Death in Regions within England 2010*. London: Cicely Saunders Institute.

Gott M, Gardiner C, Ingleton C, et al. (2013) What is the extent of potentially avoidable admissions amongst hospital in-patients with palliative care needs? *BMC Palliative Care*, 12(1), 9.

Green M and Lawson V (2011) Recentring Care: Interrogating the Commodification of Care. *Social and Cultural Geography*, 12(6), 639–654.

Greener I (2009) Towards a history of choice in UK health policy. *Sociology of Health & Illness*, 31(3), 309–324.

Hartman Y (2005) In bed with the enemy: Some ideas on the connections between neoliberalism and the welfare state. *Current Sociology*, 53(1), 57–73.

Henry, C. et al. (2015) *What's Important to Me: A Review of Choice in End of Life Care*. London. Choice in End of Life Programme Board.

Heyland DK, Tranmer J, O'Callaghan CJ, et al. (2003) The seriously ill hospitalized patient: preferred role in end-of-life decision making? *Journal of Critical Care*, 18(1), 3–10.

Higginson IJ (2003) *Priorities and Preferences for End of Life Care in England, Wales and Scotland*. London: The Cicely Saunders Foundation, Scottish Partnership for

Palliative Care and the National Council for Hospice and Specialist Palliative Care Services.

James N and Field D (1992) The routinization of hospice: Charisma and bureaucratization. *Social Science & Medicine*, 34(12), 1363–1375.

Kingfisher C and Maskovsky J (2008) Introduction: the limits of neoliberalism. *Critique of Anthropology*, 28, 115–126.

Latimer E (1991) Caring for seriously ill and dying patients: the philosophy and ethics. *Canadian Medical Association Journal*, 144(7), 859–864.

Macaden S (2011) Moving toward a national policy on palliative and end of life care. *Indian Journal of Palliative Care*, 17(Suppl), S42–S44.

Mol A (2008) *The Logic of Care: Health and the Problem of Patient Choice*. Abingdon: Routledge.

NEOLCIN (2013) *End of Life Care Co-ordination: Record Keeping Guidance*. London: NEOLCIN

NICE (2011) *Quality Standard for End of Life Care*. London, Available from: http://www.nice.org.uk/guidance/QS13.

Ong A and Collier SJ (2005) *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems*. Oxford: Wiley.

Owens J (2015) Creating an impersonal NHS? Personalization, choice and the erosion of intimacy. *Health Expectations*,18(1), 22-31.

Peart K (2004) Birth planning - Is it beneficial to pregnant women? *Australian Journal of Midwifery*, 12(1), 27–29.

Richards M (2008) The End of Life Care Strategy: Promoting High Quality Care for All Adults at the End of Life. *End of Life Care Strategy*, London: Department of Health.

Rivett G (1998) *From Cradle to Grave: Fifty Years of the NHS*. London: King's Fund.

Salecl R (2010) *Choice*. London: Profile Books.

Scott-Samuel A, Bambra C, Collins C, et al. (2013) The impact of Thatcherism on health and wellbeing in Britain. *International Journal of Health Services*, 44(1), 53–71.

Seymour J (2012) Looking back, looking forward: the evolution of palliative and end-of-life care in England. *Mortality*, 17(1), 1–17.

Seymour J, French J and Richardson E (2010) Dying matters: Let's talk about It. *British Medical Journal*, 341, 646–648.

Seymour J, Almack K and Kennedy S (2010) Implementing advance care planning: A qualitative study of community nurses' views and experiences. *BMC Palliative Care*, 9(4).

Tang ST and Chen C-H (2012) Place of death and end-of-life care. In: Cohen J and Deliens L (eds), *A Public Health Perspective on End of Life Care2*, pp. 21–34.

Thomas R, Wilson DM, Justice C, et al. (2008) A literature review of preferences for end-of-life care in developed countries by individuals with different cultural affiliations and ethnicity. *Journal of Hospice and Palliative Nursing*, 10(3), 142–161.

Veitch K (2010) The government of health care and the politics of patient empowerment: New Labour and the NHS reform agenda in England. *Law & Policy*, 32(3), 313–331.

Walter T (1994) *The Revival of Death*. London: Routledge.

Zimmermann C and Rodin (2004) The denial of death thesis: sociological critique and implications for palliative care. *Palliative Medicine*, 18(2), 121–128.