Open Research Online

The Open University's repository of research publications
and other research outputs

Social death in end-of-life care policy

Journal Item

For guidance on citations see FAQs.

Version: Accepted Manuscript

oro.open.ac.uk

Title: Social death in end-of-life care policy

Author: Erica Borgstrom

Author Affiliation: London School of Hygiene and Tropical Medicine, 15-17 Tavistock Place, London, England, WC1H 9SH

Author email: Erica.borgstrom@lshtm.ac.uk dr.borgstrom@gmail.com

Author telephone: (0044) 07580785231

To be submitted as part of special issue on social death in *Contemporary Social Science*.

Biographical note about the author: Erica is an anthropologist with an interest in medical issues and dying studies. Her work ethnographically explores end-of-life care policy and its translation into practice, as well as the experiences of those living with chronic and/or terminal illness. She currently holds the Foundation for Sociology of Health and Illness Mildred Blaxter Post-doctoral Fellowship.

Title: Social death in end-of-life care policy

Abstract: Social death denotes a loss of personhood. The concept of social death is engaged with in English end-of-life care policy that sees social death before physical death as a problem. Policy-makers posit that dying persons are likely to be subject to a social death prior to their physical death unless they play an active and aware role in planning their death, facilitated through communication and access to services. Such a view foregrounds a vision of agency and does not address Sudnow's critique of how care of the dying focuses on the body.

Word Count: 7202

Introduction

The dying trajectory for most people has become prolonged due to demographic and epidemiological changes, with more people dying in older age with multi-morbidities, including dementia (Murray, Kendall, Boyd, & Sheikh, 2005). Sociological and anthropological work around aging, dementia, and dying has suggested that the asynchronous decline of bodily and cognitive functions, often attributed to these demographic and epidemiological changes, and the current care practices used to manage this decline, may result in a form of social death, whereby people are treated as if they are already or nearly dead (e.g. Froggatt, 2001). Research on social death suggests that when it occurs before physiological death (i.e. the death of the body), it marks a loss of personhood (Lawton, 2000). These experiences of 'prolonged dying', loss of personhood, and the corresponding culturally constructed sensitivities around this, have ignited and united public and professional interest in death (Spiro 1996). Consequently, within England there has been a search for normalising 'good death' that controls this decline, both in terms of euthanasia and assisted dying (N. Richards, 2014), and in extending hospice and palliative care to general end-of-life care (Clark, 2002). In this article I outline how policy-makers have engaged with different notions of social death in constructing and justifying end-of-life care policy, as they seek to address and improve the quality of care when dying and the experience of death.

End-of-life care (EOLC) seeks to systematically address the care of the dying, and the End of Life Care Strategy (Department of Health, 2008), the leading policy document for end-of-life in England and Wales, promotes improved healthcare service provision to enable all people to experience what is considered within the policy a 'good death'. The strategy notes that 'there are distressing reports of people not being treated with dignity and respect' and that people may not be able to die in their place of choice (Department of Health, 2008:9). Therefore, the creation of English EOLC policy has been interpreted as a response to publicised negative experiences of dying people (Seymour, 2012). These reports provide a contemporary example of the critiques levelled at dying in institutions several decades ago (e.g. Illich, 1976), indicating that despite advances in medical technologies, care for the dying more generally has not necessarily improved or indeed kept pace with demographic and epidemiological shifts, and that people continue to express dissatisfaction with how death is

handled within biomedicine. In this article, I argue that EOLC policy-makers have interpreted such examples as forms of 'social death', where personhood is not respected, and have, in part, devised EOLC policy to reduce the possibly of this occurring. Coupled with a rise in consumerist healthcare more generally and the roots of EOLC in hospice philosophy, this has resulted in EOLC policy that promotes patient autonomy and agency to enable 'person-centred care'.

Although critiques have been made about current health care practices that may result in people not being treated with dignity, interpretable as a form of social death, this paper is concerned with how such practices are understood by policy-makers. Policy documents and discussions with policy-makers indicate what has come be valued and how different kinds of experience and evidence are mobilised to promote changes in practice and thinking. Consequently, policy can be viewed as a social agent: the principles and guidelines embedded in documents and speeches are used to change the processes of healthcare practice and the ways in which experiences can be evaluated (e.g. Riles, 2006).

Barbour has suggested that medical professionals and policy-makers have borrowed from the social sciences through a process that she terms 'sociolization', which is most notable in the narrative turn within medicine (Barbour, 2011). Through this process, issues that have been raised within the social sciences – such as the importance of understanding a person's biography to understand their illness experience – have migrated from social theory into healthcare policy. This article analyses if, how, and the extent to which theories around social death have found resonance within end of life care policy. In order to do this, I employ a discourse analysis of the English EOLC policy (understood loosely to include national guidelines, strategy documents, and local articulates of national strategies). This included examining select policy documents (from 2008 to early 2015), fieldnotes from events that promoted implementation of the End of Life Care Strategy in 2010 to 2012, and 13 interviews with people involved in creating and informing EOLC policy in England; I refer to them as policy-makers, and quotes from them have been anonymised to protect confidentiality. Initial data collection and analysis were part of a larger study about choice in EOLC and a further description of methods can be found in Borgstrom (2014). Initial analysis, for this article, sought explicit references to the concept of social death and further analysis drew on the theoretical literature, which associates social death with a lack of personhood. I therefore identified occasions when policy-makers alluded to possible cases of social death, through descriptions of care that 'lacked dignity' or were 'distressing' or where

personhood was somehow denied or not respected. Whilst these examples were not as frequently used within the policy discourse as the concept of 'good death' was (although they can be related), as I demonstrate below, they are used to mobilise and justify the need for particular elements of EOLC policy. In this way, part of the sociolization process is incorporating theoretical ideas about social death into the policy rhetoric.

In order to explore how policy-makers engage with the concept of social death in the context of EOLC, I first sketch what EOLC policy is and how it has been formed within England over the last couple of decades. I then discuss the data, providing examples of how social death was discussed by policy-makers and the conclusions they drew from their interpretations of occurrences or possibilities of social death (always prior to physiological death). The last section challenges the use of concept of social death by policy-makers - both how it is used and the ability of the proposed 'solutions' to counter the issues that concerned them.

End-of-life care policy

End-of-life care is a relatively new field of medicine that has its roots in cancer care, hospice philosophy, and palliative medicine (Seymour, 2012), although it is applied more broadly across diagnoses and clinical settings beyond these specialities. Within England, approximately 500,000 die each year with most expected to have some EOLC or contact with health services towards the end of life (Hughes-Hallett, Craft, & Davies, 2011).To address the care of the dying, end-of-life care is promoted through national policy, specifically the End of Life Care Strategy (Department of Health, 2008). This sought to change the provision of care for dying persons, improving access and quality across the country regardless of diagnosis or healthcare setting. In interviews, a wide range of policy-makers said that the purpose of the strategy was to 'affect change' and to 'take the excellent and make it the norm'. The strategy focused on patient choice and home death, and acted as a lever for changes in practice and related government policies, such as how to fund health and social care (Borgstrom, 2015).

Growing out of the NHS Next Stage Review (House of Commons Health Committee, 2008), disease-specific frameworks (e.g. Department of Health, 2001), and work done by the relatively new National End of Life Care Programme (NEOLCP), the strategy was developed within the Department of Health. Members of the advisory board and working groups who developed the policy were primarily not civil servants but came from diverse professional

backgrounds, including the third sector, academic research, and those with professional and/or personal experience in palliative and end-of-life care. Developing policy was viewed by those interviewed as a collaborative process, with many opportunities for 'partnerships', which nevertheless involved negotiating values and priorities. Policy-makers described their role as promoting 'best practice' to address patient and professional experience of daily practice and 'what they know needs improving', and thought about how they could 'add value' to what already happens. For example, Jenny (a clinician and researcher who was involved since the initial discussions about national policy in this field) described creating EOLC policy (and consequent service re-development) as 'a way of changing things so the right things happen at the right time'. The resulting outcome from the strategy was a three-prong approach to the care of the dying: a care pathway with an emphasis on early identification and communication about dying and managed care, raising national awareness about dying, and improving professional education and funding.

Four annual reviews have been published marking the progress made from implementing the End of Life Care Strategy (Department of Health, 2009, 2010, 2011, 2012). Year-on-year there have been improvements across all indicators of quality in EOLC as defined by policy-makers (M. Richards, 2014), yet several high-profile reports, including the removal of the Liverpool Care Pathway previously promoted by EOLC policy, suggest that care of the dying has not consistently improved across the country, and that many people do not experience a 'good death' as end-of-life care policy guidelines suggest (Dixon, King, Matosevic, Clark, & Knapp, 2015; Neuberger et al., 2013; Parliamentary and Health Service Ombudsman, 2015). The End of Life Care Strategy is currently being reviewed, but related consultations suggest that patient choice and dignity will remain important themes (The Choice in End of Life Care Programme Board, 2015).

Social death within end-of-life care policy

As policy-makers are continuously engaging with wider social changes and debates, and some of them are academic and clinical researchers, it can be expected that their draws on ideas informed by social issues and theory. The evidence for this flow of ideas can be found in both explicit references to theoretical concepts or more implicitly in how issues are framed and discussed. In this section, I outline how 'social death' is mobilised by policy-makers as a

possible occurrence in daily clinical practice in order for them to make arguments about changing how dying persons are cared for.

The term 'social death' does not feature within the national End of Life Care Strategy, and perhaps it would be unreasonable to expect it to be in the policy document text. Firstly, within academia there is a considerable debate and variation about what the term means and who it applies to (Sweeting & Gilhooly, 1992); such ambiguity may not be useful when setting out guidelines for healthcare. Secondly, policy documents have their own kind of language (Corson, 1988) and EOLC policy is targeted at an interdisciplinary audience; therefore it is understandable that policy-makers have not adopted what can be viewed as social science 'jargon' in a healthcare document. However, if the concept has informed the thinking of policy-makers, either direct or indirect references to it (or even references to academic literature discussing the idea) can indicate its influence in thinking about the care of the dying. This is particularly pertinent in texts and events around main policy initiatives that seek to educate practitioners about the intention and direction of policy.

For example, within a book that outlines how the End of Life Care Strategy can be operationalised, the authors, who are all part of the National Council of Palliative Care, an organisation that informs and promotes EOLC policy, sets out the policy and strategy within the 'context and philosophy of end of life care' (A Hayes et al., 2014). One chapter explains the need for EOLC policy in England and the rationale behind it, drawing considerably on sociological references, including medicalisation critiques and the changing nature of dying in society. As part of this, there is over a page dedicated to describing 'social death and marginalised dying' (pp.15-16). The authors note the historical origins of the term in Sudnow's work (Sudnow, 1967) and suggest that social death is 'a phenomenon that can be as real today as it was when first observed' (p.15). So whilst the term social death does not feature directly in the End of Life Care Strategy, its inclusion in this book suggests that it has informed the construction of contemporary EOLC policy, or at least is being used to justify a need to change practices.

In my analysis, there were three ways in which social death was discussed by policy-makers in the context of EOLC policy; each approach has its own section below. Each way of discussing social death was mobilised by policy-makers to do something different by highlighting specific aspects about death, dying, and care that needed (from their perspective) addressing. In doing so, each version or possibility of social death asserts different values and

serves to illustrate the connections policy-makers were making and creating between thinking about death, personhood, and care practices.

Exclusion, isolation, and Advance Care Planning

The first category includes a direct reference to social death and sociological literature on the topic, including how the concept of social death has been merged with notions about marginalisation and isolation, drawing on the book mentioned above. In the book section, social death is identified in people being 'gradually removed from mainstream society… [and] may accompany isolation and loss of a sense of being' (Hayes et al., 2014,p.15). Specific research from the late 1990s and early 2000s on older people and care homes is cited to describe how care of the dying may result in the exclusion of the dying person. Social death is identified as a result of a series of processes that separate the person from the body whilst also marginalising the person's agency and ability to interact in society. In effect, these examples highlighted how people were, as a result of the care they received, no longer being viewed as active agents in their own lives. Since EOLC is based on a holistic, person-centred philosophy that seeks to treat and care for the 'whole person', this kind of social death occurring before physical death is problematic as it signifies that person-centred care is not being delivered or realised. Such reduction in interaction before bodily death is interpreted within this context as being premature, and therefore socially and morally inappropriate.

The book's authors note that the hospice movement, which has strongly influenced end-of-life care policy, has 'sought to counter this exclusion of people who are dying' through an emphasis on living until death (Hayes et al., 2014,p.16). End-of-life care then is implied as an appropriate response, or even preventive measure, to social death. Readers of the book are encouraged to think about people they know currently receiving care who may be the subject of 'social death' and how they can 'turn exclusion into inclusion' (Hayes et al., 2014,p.16). As the purpose of the book is to suggest how to apply the EOLC strategy to provide person-centred care, further reading of the text suggests that in this context potential solutions include openly talking about death, especially to facilitate advance care planning.

Advance care planning encourages people to make statements about treatment decisions in advance of those decisions being required (Thomas & Lobo, 2011). In the context of EOLC, it is used as a way of opening up conversations between staff, patients, and families about what the dying process may entail, and how it can be managed (Waldrop & Meeker, 2012). People are encouraged to write declarations of their 'choices' for care and treatment by

actively imagining what dying and death may be like. For example, within the Preferred Priorities for Care document that is endorsed by national EOLC policy, people are asked 'what are your preferences and priorities for your future care' (Storey & Betteley, 2011). In the interviews I conducted, policy-makers suggested that people could think of elements of care from 'the room you're in', 'what's on the telly', to refusing certain treatments. Making such choices – and having them respected by others – was stated by policy-makers as evidence of 'living until death' and therefore an element of personhood.

Importantly, healthcare professionals are encouraged to consult these documents and patients' wishes when making treatment decisions (Wilson et al., 2013), rejecting a more paternalistic model of care. By emphasising the importance of advance care planning as part of the larger end-of-life care pathway, the role of patient autonomy throughout the journey is stressed within the policy discourse. The patient is viewed as having an active voice and decision-making capabilities to affect the kind of care they receive (Thomas & Lobo, 2011). Sarah, who worked within a national disease-related charity, stated that care should reflect patient choice 'as they are still a person… [even if] capacity diminishes, emotions don't diminish'. This in turn changes dying from something that is strictly clinically managed and done to the body, to something that engages and is in line with the patient's sensibilities. As summed up by Jenny, a marker of good care at the end of life is care that it is 'aligned with people's preferences', which she, like other policy-makers assumed and advocated can be done through advance care planning. The connection between choice and quality of care is further stated in more recent policy documents, like in the review of choice in end of life care, which unequivocally stated that there is a link between 'high quality end of life care' and people's care choices (The Choice in End of Life Care Review Board, 2015:13).Through this logic, respecting patient choice is equated to respecting the person, which in turn is a signifier and lever of good care and means a premature social death is less likely to occur.

Inequality, equity, and social death

The second category is from the same source, although it also came up in the interviews, and includes a direct reference to social death and social science literature on the topic. Within the policy discourse, social death was not something that all patients are at risk of experiencing. There is a particular concern that certain sub-groups of the population, such as older persons who experience frailty or those dying from non-malignant conditions, may be at greater risk of poor end of life care that ignores their dying or treats them as if dead (A Hayes et al.,

2014). To support these claims, sociological and anthropological studies of care and dying are cited (Froggatt, 2001; Hockey, 1990; Komaromy, 2000).

For example, Froggatt (2001) and Hockey's (1990) work in care homes is referenced to highlight how care home staff manage dying as decline by placing people in other rooms. The authors of the book note that language used to refer to people can serve to mark this transition and social death. Similarly, they suggest such practices can occur as 'communication and interaction with the person who is dying become increasingly difficult' (Hayes et al. 2014, p.15). Whilst these examples may apply primarily to older persons (without mentioning potential ageism) who experience frailty and dementia, it is implied within the text that people who have other conditions – such as neurological conditions – may also have similar 'isolating' experiences.

This is a concern for policy-makers as patients who have non-malignant conditions have, historically, not had as much support from palliative care services compared to those dying of cancer, and are less likely to have done advance care planning (Ahmed, Bestall, Ahmedzai, Payne, & Noble, 2004; Walshe, Todd, Caress, & Chew-Graham, 2009). This is a particular concern, as Sarah noted, for patients who may 'lose capacity as cognitive function declines'. These concerns are supported by recent research highlighting the varying levels of access across diseases (Dixon et al., 2015). Although not fully articulated in the texts or interviews, what is at stake in this reference to social death is that healthcare professionals treat dying people differently based on their diagnosis, even if people have similar clinical and supportive needs. Since policy-makers are seeking to promote the use of EOLC for all, highlighting sub-groups who may not have access, and noting that this access may be a result of care practices that negate their personhood, serves to demonstrate a need to re-design and re-align healthcare practices.

Good death, dignity, and communication

The last category encompasses inferences about social death in relation to concepts like 'good death' and 'dignity'; whilst these are highly problematic in themselves, they are treated as readily understood and shared values within the policy discourse (Borgstrom, 2014, 2015). In the policy events and interviews with policy-makers, it was not unusual for people to refer to examples where the quality of care was not optimal as part of their discussions about why EOLC policy was needed. These were often quickly contrasted to what a 'good death' could be, which is first and foremost defined as being treated as 'an individual, with dignity and

respect' (Department of Health, 2008:9) in the End of Life Care Strategy. The way in which people drew on these examples highlighted ways in which dying people and their families may not be treated as persons within the healthcare system, or where professionals have 'turned away' from death and dying, perhaps viewing it as a failure (M. Richards, 2008).

For example, one interviewee, John (a doctor and national policy representative) referred to a tabloid newspaper article about an older woman being treated as a 'slab of meat' by healthcare professionals in a hospital, leading to her not having a 'good death' as reported and interpreted by John. The article implied that, from the family's perspective at least, the hospital staff did not adequately care for the woman, treating her as an object, and considered their mother as already dead. Whilst I have heard such scenarios re-interpreted by healthcare professionals as conforming to guidance (particularly prior to the Liverpool Care Pathway being withdrawn), John stated that no one should have such an experience or feel like that is what has happened. In this context, (a premature) social death can be understood as not being adequately cared for and therefore preventing a good death, however defined, at the end of life.

Instead, he suggested that staff need to communicate their actions and intentions with patients and families better, 'explaining the process of death to them'. He did not deny that such scenarios can occur, or that it may be a form of neglect; he suggested that it was a result of miscommunication and misunderstanding between families and professionals, which serves to give the impression that healthcare professionals do not treat dying patients as persons. As an alternative, John suggested that there is a need to change public expectations and professional caring practices to be more open about dying. His logic was that such openness would counter the interpretation of care highlighted in the tabloid headline. Therefore, it is not the care practices themselves that are at stake here or the cause of social death; instead, they have been reduced to (mis)communication.

This mode of 'open awareness' as several policy-makers referred to it (explicitly drawing on Glaser and Strauss' theory of awareness contexts – see Glaser & Strauss, 1965) requires healthcare professionals to identify dying earlier and to openly communicate with patients and families that death is likely and approaching (Leadership Alliance for the Care of Dying People, 2014; National Council for Palliative Care & Dying Matters, 2011). For instance, the General Medical Council's advice is that doctors discuss end-of-life care with patients well in advance of the person's last few days (GMC, 2010). Sociological research about the

effectiveness of open awareness and documenting patient preferences about the end of life is used within policy documents and events to provide evidence for the ability of this kind of care practice to enable patients to be persons up until their bodily death (e.g. Seale, Addington-Hall, & McCarthy, 1997). Essentially, policy-makers believe that 'people want to deliver good care' (Jenny) and 'empowering people to talk… is fundamental to good end of life care' (Hayes et al., 2014:37).

In order to promote better communication at the end of life, John, like other policy-makers suggested that training in EOLC needs to improve across all healthcare professions. Amy, who led policy for a national palliative care-oriented charity and actively lobbied government, said that her organisation pushed for 'mandatory training in end of life care' when discussing national policy with politicians and civil servants. Not only would training help address patient dignity issues, she considered it vital to addressing staff burnout and organisationally readdressing priorities that may lead to uncaring practices. Steve, who had a similar role to Amy, suggested that many healthcare professionals had a 'lack of confidence' that may mean they do not talk or engage with patients, inadvertently causing them to provide sub-standard care. Policy-makers like Steve and Amy use case examples of 'bad care' and studies that demonstrate undertraining and professional taboos around death to persuade politicians that care of the dying needs reforming. Encouraging discussions about death, dying and bereavement was viewed as a way to improve the professional and political awareness of these topics. A focus on EOLC education and openly discussing dying, not just within clinical practice but more generally as well, is consequently viewed by some policy-makers as a direct way to alter organisational and societal processes that may lead to 'social death'.

Overall
The above examples of how policy-makers discuss social death demonstrate how policy-makers can think of social death as an occurrence and a potential regular practice, both of which are viewed as antithetical to 'good' end-of-life care. Framing social death as problematic then provides an avenue for opening up a public and professional discussion about what care of the dying looks like and should look like. Bringing the idea of social death explicitly or implicitly to the fore enables policy-makers to make claims about what needs to change in current end of life care to enable people to be treated as persons until they die and

to enable them to have a 'good death'. The solutions suggested by policy-makers, unsurprisingly, support the philosophical roots of end of life care policy that view best care as holistic, patient-centred, and supportive of patient autonomy. By referring to instances where social death may occur, policy-makers are effectively highlighting gaps in current or past practice that does not align with the philosophy and practice of care they are advocating. Policy-makers suggest then that EOLC policy, promoting increased training and communication, can readdress issues of social death by asserting the centrality of the person – through communication – during the transition from actively living to being dead. As Jenny said, she hoped EOLC policy promoting advance care planning would 'prevent medicalisation of dying...[by enabling people to] live in the context of their dying'. Ultimately, social death is mobilised by policy-makers within end of life care discussions to provide an impetus for changing care practices in a way that frames dying as a trajectory that can result in a good death.

Discussion

It is commendable that policy-makers actively want to improve the experience of people who are dying, and have acknowledge that previous critiques resulted from how care was managed. By looking at how policy-makers engage with the concept of social death and how they mobilise it to justify aspects of end-of-life care policy, it is apparent that it is being used to portray particular understandings of what it means to be a person and what sociality is like. Policies that seek to minimise the likelihood of a person experiencing social death before physical death focus on the patient's agency and communication. However, these ideas of social death do not address the core of Sudnow's original critique when he coined the term 'social death', that argued that social death results from a focus on the body. This section outlines this disconnect and suggests that it provides an explanation for continued critiques of the care of the dying.

The alternatives or solutions to prevent social death, as suggested by policy-makers, focus around advance care planning, equal access to care, and communication and training about dying. At the heart of these, and within the national End of Life Care Strategy more generally, lies the thread that talking about dying can improve the care and experience of death. In the context of social death, such talk can serve to re-align social death and physiological death, so the logic goes, by enabling, for example, preferences to be expressed

and followed, and for professionals to educate patients and families about the dying process. In this sequence, communication is tied with agency – being able to make information known and to enable others to act accordingly – and policy-makers connect these intrinsically with 'dignified care'. If social death is understood theoretically as representing a loss of personhood, in these examples, agency (or being treated as if one has little agency within the healthcare system) and the ability to verbally exchange information are viewed within this context as key elements of personhood that are at risk of being prematurely 'lost' towards the end of life.

At this point, this way of describing and responding to social death is consistent with the social science literature of the late 1990s and early 2000s, which policy-makers draw on. However, policy-makers also make reference to Sudnow's work and it is here that I wish to problematize the use of social death in this context and the over-emphasis on communication and preference as expression of sociality and personhood. Sudnow's original work on social death was about how practices may change as a result of healthcare professionals recognising and prognosticating dying and death, which is a core element of end of life care. Spotting that there was a phasing out of the attention given to dying patients, Sudnow defined social death as the point 'at which a patient is treated essentially as a corpse' (1967:74) although his/her body may still be physiologically functioning. This definition of social death serves to outline the practices, within the hospital settings under study, that mark how socially relative attributes of the person ceased to be operative in the way staff interacted with patients. For example, he describes how autopsy permits were filed and obtained from relatives before a person died, pre-empting a patient's death. It is apparent in Sudnow's writing that social death is not just about an asocial treatment of the person per se, but the increasing importance of *the body* as the focal object in how the patient is discussed and how the dying process is managed. Others have proposed that biomedicine marginalises both the people and the processes involved in dying and caring for the dying as it does not know how to handle death in the absence of a cure or ability to restore the body's functioning (Christakis, 2001).

The examples of social death provided by policy-makers highlight the asocial treatment of the dying person; however, as the examples stand and are interpreted by policy-makers, they do not go as far as to suggest that social death can be the result of medicalised dying, where the body is foregrounded in care practices. Another interpretation of the 'slab of meat' case could read that staff were focusing on biomedical care, which to the family at least appeared as dehumanised treatment. I am not trying to justify their actions or privilege one

interpretation over another; instead, I make this observation to highlight the selective ways in which policy-makers' engage with the concept of social death. In doing so, they are able to suggest solutions that consider a particular version of what 'being social' means – expressing preferences and engaging in communication – rather than problematize how the care of the dying can and does see the dying body as an object.

End-of-life care is often cited as being person-centred (A Hayes et al., 2014), and in the practice of caring for the dying, healthcare professionals are tasked with managing decline and the elements of personhood discussed above, including agency. End-of-life policy is said to have come of age in England with the release of the national strategy in 2008, and there has been some evidence that advance care planning and the EOLC strategy have enabled more people to have 'good deaths' (Department of Health, 2012). Yet there have been several high-profile scandals about poor care of the dying since then. This includes the Mid-Staffordshire scandal where poor care was leading to higher than average mortality rates within the hospital and the retraction of the Liverpool Care Pathway. This is perhaps suggestive that the kind of care management that can lead to premature social death, as feared by EOLC policy-makers, has continued, despite changes in EOLC policy and training. This is in part due to a wider healthcare culture that focuses on procedure rather than processes or persons (Napier et al., 2014; Neuberger et al., 2013; *The Mid Staffordshire NHS Foundation Trust Public Inquiry*, 2013) and perhaps a need for a longer period since the release of the End of Life Care Strategy to evaluate its ability to change practices. Nevertheless, although there has been some progress in changing the care of the dying to promote person-centred care, there are still instances that could be described as (premature) social death within the NHS today.

Healthcare practice can still result in instances of social death because EOLC policy and practice is built around a notion that bodily death is an identifiable and definable event, around which care can be organised (Froggatt, 2007:243). This lies at the core of Sudnow's critique of how dying persons were cared for. The actions promoted by EOLC policy as a way of negating social death involve people to be aware of their terminal condition, to plan for their future care, and to openly talk about their preferences. However, it is the assessment of the patient's body by professionals that drives this care management, noting aspects that are important to the medical and palliative care model rather than what might be important to the dying person (Kellehear, 2009). Even where patient preference is trumpeted, through processes like advance care planning and the ability to provide care towards the end of life

that is in line with patient choice, the emphasis in (primarily) on how to manage the dying body. This stance is part of an institutional agenda that enables efficient management of dying people and their preferences (Green, 2008). Medical systems have a 'vested interest in people being aware of their impending deaths' (Pery & Wein, 2008:400). Yet, this approach does not adequately accommodate those who may wish to not participate in advance care planning (Barclay, Momen, Case-Upton, Kuhn, & Smith, 2011) nor does it realise the messiness of the dying experience (Strange, 2009). Fundamentally, although EOLC seeks to draw on patient preferences, there is a still a strong focus on the management of the dying body, evident in the EOLC strategy and suggestion that there needs to be better communication and training about what dying is like.

I would argue, however, that focusing on communication and advance care planning, in and of themselves, will not manage to change how healthcare professionals (or care home staff, etc) orient themselves to the care of the dying. These policies go some way in promoting a different way of thinking and approaching the care of the dying, that seeks to foreground the dying person, but do not address the nature of dying and the clinical care practices that seek to manage physiological changes. For this to occur, policy-makers need to challenge themselves using Sudnow's original critique and the medical treatment of persons as bodies, rather than focus on an understanding of social death that rests primarily with personhood and agency.

Conclusion

The concept of social death is used to describe an ontological deficit of the person. Policy-makers working in EOLC have drawn on the concept of social death in devising and justifying policy recommendations to change the care of the dying. In their interpretations, social death can occur from care practices that exclude the dying person and may disproportionally affect people dying from non-malignant conditions. To address this, EOLC policy suggests involving patients in planning for their care and place of death and increasing awareness about death and dying. Agency, supported by information, is therefore considered to be key elements of personhood. However, these interpretations of social death and personhood uphold mind/body dualism (despite being part of 'person-centred care') and the solutions do not in and of themselves radically challenge the foregrounding of the body in the care of the dying.

References:

Ahmed, N., Bestall, J. C., Ahmedzai, S. H., Payne, S. A., & Noble, B. (2004). Systematic review of the problems and issues of accessing specialist palliative care by patients, carers and health and social care professionals. *Palliative Medicine*, *18*(6), 525–542.

Barbour, R. S. (2011). The Biographical Turn and the "Sociolization" of Medicine. *Medical Sociology Online*, *6*(1), 15–25.

Barclay, S., Momen, N., Case-Upton, S., Kuhn, I., & Smith, E. (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.

Borgstrom, E. (2014). *Planning for Death? An Ethnographic Study of English End-of-Life Care*. University of Cambridge, Cambridge. Retrieved from https://www.repository.cam.ac.uk/handle/1810/245560

Borgstrom, E. (2015). End of life care strategy and the Coalition Government. In L. Foster & K. Woodthrope (Eds.), *Death and Social Policy in Challenging Times* (in press). Basingstoke: Palgrave Macmillan.

Christakis, N. A. (2001). *Death Foretold: Prophecy and Prognosis in Medical Care*. Chicago: University of Chicago Press.

Clark, D. (2002). Between hope and acceptance: the medicalisation of dying. *BMJ*, *324*, 905–907.

Corson, D. (1988). Making the language of education policies more user-friendly. *Journal of Education Policy*, *3*(3), 249–260.

Department of Health. (2001). *The NHS Cancer Plan*. London: Crown.

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

Department of Health. (2009). *End of Life Care Strategy: First Annual Report*. London.

Department of Health. (2010). *End of Life Care Strategy: Second Annual Report*. London.

Department of Health. (2011). *End of Life Care Strategy: Third Annual Report*. London.

Department of Health. (2012). *End of Life Care Strategy: Fourth Annual Report*. London.

Dixon, J., King, D., Matosevic, T., Clark, M., & Knapp, M. (2015). *Equity in the Provision of Palliative Care in the UK: Review of Evidence*. London.

Froggatt, K. (2001). Life and death in English nursing homes: sequestration or transition? *Ageing and Society*, *21*(3), 319–332.

Froggatt, K. (2007). The "regulated death": a documentary analysis of the regulation and inspection of dying and death in English care homes for older people. *Ageing and Society*, *27*(2), 233–247.

General Medical Council. (2010). *Treatment and care towards the end of life: good practice in decision making*. London.

Glaser, B. G., & Strauss, A. L. (1965). *Awareness of Dying*. Chicago: Aldine.

Green, J. W. (2008). *Beyond the Good Death: The Anthropology of Modern Dying*. Philadelphia: University of Pennsylvania Press.

Hayes, A., Henry, C., Holloway, M., Lindsey, K., Sherwen, E., & Smith, T. (2014). *Pathways through Care at the End of Life*. London: Jessica Kingsley Publishers.

Hockey, J. (1990). *Experiences of Death: An Anthropological Account*. Edinburgh: Edinburgh University Press.

Hughes-Hallett, T., Craft, A., & Davies, C. (2011). Palliative Care Funding Review: Funding the Right Care and Support for Everyone.

Illich, I. (1976). *LImits to Medicine; Medical Nemsis: The Expropriation of Health*. Harmondsworth: Penguin.

Kellehear, A. (2009). The Study of Dying. Cambridge: Cambridge University Press.

Komaromy, C. (2000). The sight and sound of death: the management of dead bodies in residential and nursing homes. *Mortality*, *5*(3), 299–315.

Lawton, J. (2000). *The Dying Process: Patients' experiences of palliative care*. London: Routledge.

Leadership Alliance for the Care of Dying People. (2014). One Chance to Get It Right: Improvinig People's Experience of Care in the Last Few Days and Hours of Life.

Murray, S. A., Kendall, M., Boyd, K., & Sheikh, A. (2005). Illness trajectories and palliative care. *British Medical Journal*, *330*, 1007–1111.

Napier, A. D., Ancarno, C., Butler, B., Calabrese, J., Chater, A., Chatterjee, H., … Woolf, K. (2014). Culture and health. *The Lancet*, *384*(9954), 1607–39.

National Council for Palliative Care, & Dying Matters. (2011). *Dying - Doing It Better*. London.

Neuberger, J., Aaronovitch, D., Bonser, T., Charlesworth-Smith, D., Cox, D., Guthrie, C., … Waller, S. (2013). *More Care, Less Pathway: A Review of the Liverpool Care Pathway*. London: Independent Review of the Liverpool Care Pathway; Crown.

Parliamentary and Health Service Ombudsman. (2015). *Dying without dignity*. London.

Pery, S., & Wein, S. (2008). The dying patient: the right to know versus the duty to be aware. *Palliative & Supportive Care*, *6*(4), 397–401.

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. f

Richards, M. (2014). Foreword. In A. Hayes, C. Henry, M. Holloway, K. Lindsey, E. Sherwen, & T. Smith (Eds.), *Pathways through Care at the End of Life* (pp. 9–10). London: Jessica Kingsley Publishers.

Richards, N. (2014). The death of right-to-die campaigners. *Anthropology Today*, *30*(3), 14–17.

Riles, A. (2006). Documents: Artifacts of Modern Knowledge. Ann Arbor, MI: The University of Michigan Press.

Seale, C., Addington-Hall, J., & McCarthy, M. (1997). Awareness of dying: Prevalence, causes and consequences. *Social Science & Medicine*, *45*(3), 477–484.

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

Storey, L., & Betteley, A. (2011). Preferred priorities for care: an advance care planning process. In K. Thomas & B. Lobo (Eds.), *Advance Care Planning in End of Life Care* (pp. 125–131). Oxford: Oxford University Press.

Strange, J.-M. (2009). Historical approaches to dying. In A. Kellehear (Ed.), *The Study of Dying* (pp. 123–146). Cambridge: Cambridge University Press.

Sudnow, D. (1967). *Passing On: The Social Organization of Dying*. Upper Saddle River, NJ: Prentice-Hall.

Sweeting, H. N., & Gilhooly, M. L. M. (1992). Doctor, Am I Dead? A Review of Social Death in Modern Societies. *Omega: Journal of Death and Dying*, *24*(4), 251–269.

The Choice in End of Life Care Programme Board. (2015). *What's Important to Me: A review of choice in end of life care*. London.

The Mid Staffordshire NHS Foundation Trust Public Inquiry. (2013). Retrieved from he Mid Staffordshire NHS Foundation Trust Public Inquiry

Thomas, K., & Lobo, B. (2011). *Advance Care Planning in End of Life Care*. Oxford: Oxford University Press.

Waldrop, D. P., & Meeker, M. A. (2012). Communication and advanced care planning in palliative and end-of-life care. *Nursing Outlook*, *60*(6), 365–9.

Walshe, C., Todd, C., Caress, A., & Chew-Graham, C. (2009). Patterns of access to community palliative care services: a literature review. *Journal of Pain and Symptom Management*, *37*(5), 884–912.

Wilson, C. J., Newman, J., Tapper, S., Lai, S., Cheng, P. H., Wu, F. M., & Tai-Seale, M. (2013). Multiple Locations of Advance Care Planning Documentation in an Electronic Health Record: Are They Easy to Find? Retrieved from http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0472