

Choice and compassion at the end of life: a critical analysis of English policy discourse (2008 to early 2015)

Erica Borgstrom (University of Cambridge) & Tony Walter (University of Bath)

Accepted for publication by *Social Science and Medicine* on 4 May 2015

Abstract

End of life care in England has recently been framed by two very different discourses. One (connected to advance care planning) promotes personal choice, the other promotes compassionate care; both are prominent in professional, policy and media settings. The article outlines the history of who promoted each discourse from 2008 to early 2015, when, why and how and this was done. Each discourse is then critically analysed from a standpoint that takes account of bodily decline, structural constraints, and human relationality. We focus on the biggest group of those nearing the end of their life, namely frail very old people suffering multiple conditions. In their care within contemporary healthcare organisations, choice becomes a tick box and compassion a commodity. Informed choice, whether at the end of life or in advance of it, does not guarantee the death the person wants, especially for those dying of conditions other than cancer and in the absence of universally available skilled and compassionate care. Enabling healthcare staff to provide compassionate, relational care, however, implies reversing the philosophical, political and financial direction of healthcare in the UK and most other Anglophone countries.

Keywords

England, end of life care, choice, compassion, discourse, old age, relational ethics, governmentality

Research Highlights

- The ‘choice’ agenda arises out of (cancer) palliative care.
- The ‘compassion’ agenda arises out of elder care scandals.
- Compassion signifies care as a relationship rather than a commodity.
- Compassion can be undermined by an overemphasis on autonomous individuals.

Introduction

In the 1950s and 1960s, the UK hospice – later palliative care – movement pioneered holistic, humanistic end-of-life care (EOLC), and the UK continues to be widely looked to as an international leader in palliative care (EIU, 2010). Increasing longevity, however, means that in advanced industrial societies twice as many people now die with multiple morbidities, frailty and/or dementia at the end of a long life, than die of the cancers on which palliative care’s expertise is based (Lynn and Adamson, 2003). Current models of palliative and EOLC may not meet the needs of this changing demographic (Moorhouse & Mallery, 2010). Consequently, both politically and publically there is a sense that providing good care for those in the ‘fourth age’ is challenging (Lloyd, 2004). How the UK is adapting its expertise in palliative care to develop EOLC policies for this newly dominant scenario is therefore of international interest.

In the context of death, the rhetorics of choice and compassion have a long history and are frequently used together. Both terms have been used to lobby for assisted dying in different countriesⁱ, when promoting advance directivesⁱⁱ, and to describe idealised ‘good deaths’ (Green, 2008). In this article, we analyse a) how discourses of choice and of compassion became detached from each other in English EOLC policy discourse 2008 – early 2015; and b) what this reveals about the challenges of developing EOLC strategies for the frail elderly. We focus on ‘choice’ as the dominant rhetoric in England’s *End of Life Care Strategy* (DH, 2008) and its public education offshoot

Dying Matters; and 'compassion' (or the lack thereof) as the dominant trope in scandals about the treatment of (primarily) frail, elderly people and in official responses to these scandals. Though many practitioners may see enabling patient choice as a way through which care is effected, Borgstrom (Borgstrom, 2014) found that the 2008 policy focus on patient choice became in practice a tick-box exercise of recording such choices, not least in order to meet targets, side-lining the relationships that are at the heart of good care. The media and political response to the EOLC scandals was to call not for more or better informed choice, but for compassionate care, and by early 2015 it was officially acknowledged that universally available high quality care is necessary for patient 'choice' to be meaningful (Henry, 2015).ⁱⁱⁱ

Our aim is not to favour one discourse over the other, nor to offer an alternative, but to invite readers to reflect on how discursive power operates. Our first two sections outline the backgrounds of the choice and compassion discourses in relation to contemporary EOLC in England. We then go on to highlight the constraints these concepts face in (healthcare) practice, both in terms of difficulty in translating policy into practice and in terms of the relative under-theorising of the language used. In both cases, the language used – choice and compassion – is employed to shift not only the language of EOLC but also the culture of care. Whereas media discourses tend to portray both choice and compassion as individual actions, we focus – as do some policy documents – also on the contexts which shape such actions and the structures that enable or disable agency. We also assume, more than policy documents do, that actors are not isolated individuals making rational choices in their own interests, but are social beings embedded in networks of relationships and often concerned for other family members as much as for themselves. We argue that, particularly in the context of caring for frail persons towards the end of life, these discourses and how they are being translated into practice may be limited in realising the values of care that they seek to embody. This is due to the focus of both discourses on the individual – either patient or healthcare professional – rather than a more relational understanding of caring. We therefore reflect on the tensions between

agency and structure in current EOLC discourses in order to conceptualise how EOLC can meet the challenges presented by changing demographics and recent scandals.

History

1) Choice

Rather than focus on when someone dies, as assisted suicide is illegal in England, 'choice' within EOLC promotes the right of patients to choose *where* they wish to die, who they wish to care for them, whether they would wish active treatment, for example for infections, if already very frail or seriously ill, and the circumstances in which they would wish to be resuscitated (DH, 2008). This we refer to as the *choice* discourse or agenda within English EOLC policy.

The paradigmatic case here is the End of Life Care Strategy (DH, 2008). In its 168 pages, the word *compassion* makes no appearance whereas the word *choice* appears 44 times, referring most frequently to patient choice, either directly or through programmes that support it such as the Delivering Choice Program or the NHS Choices website. This emphasis is remarkable because the palliative care movement which informed the Strategy has long emphasised holistic care of the whole person within a family context – care which includes but is not dominated by autonomous individuals making informed choices. The emphasis on choice is also remarkable because it is not found to such an extent in comparable strategies from other Anglophone countries, despite an international interest in patient-centred advance care planning.^{iv} Though the New Zealand strategy mentions choice seven times and makes no reference to compassion (Ministry of Health, 2001), the Canadian strategy makes no reference to choice but mentions compassionate care twice (Minister of Health, 2007); the Australian strategy makes no reference to compassion, mentioning choice only once (Commonwealth of Australia, 2010). The EOLC policy in the UK therefore serves as a case in point for how a particular discourse around choice shapes how EOLC is imagined and managed.

The thinking behind the need for people to make choices is elaborated by Dying Matters (DM), a publicly funded coalition mandated by the Strategy to raise awareness of death, dying and bereavement in England and Wales.^v Encompassed in its strapline 'Dying Matters – Let's talk about it', DM's premise is that talking about death and one's wishes about EOLC and post-death arrangements can enable people to have the deaths they want. Targeting both the general public and health professionals, DM promotes such conversations about the end of life and warns of the perils of not talking and not making informed choices about how one wishes to die.

This agenda represents a specifically British version of what in North America has long been termed the death awareness movement (Attig & Stillion, 2015): the (so called) death taboo is challenged and broken through talk (Walter, 1994; Zimmermann, 2004). The concepts of death denial and the death taboo – though problematic both as social science concepts (Kellehear, 1984) and as used by healthcare practitioners (Borgstrom, Barclay, & Cohn, 2013) – remain central to this health-political agenda (Lofland, 1978), for they indicate that people would naturally speak about death and dying were it not for an unhelpful socially constructed taboo. It is not just that people *ought* to speak, but that it's *natural* to speak. Thus discourse redefines reality (Armstrong, 1987; Borgstrom, 2014).

DM's ideas and personnel originate in hospice and palliative care, rather than medical specialties such as geriatrics and circulatory medicine which in the Anglophone world typically lie outside the death awareness movement. Starting with the work of Cicely Saunders in the 1950s and 1960s, hospice and palliative care have greatly improved care for people dying of cancer (Seymour, 2012). Cancer has a relatively clear terminal trajectory which, once curative treatment has proved ineffective, health professionals can predict with some – by no means total – certainty (Murray, Kendall, Boyd, & Sheikh, 2005). Informed conversations may therefore be had with, and informed decisions made by, persons as they face their end.

In the UK, cancer care in general, and hospice care in particular, is better resourced and rated more highly by families than is care for the other major killers: stroke, heart disease and, most significantly, multiple conditions among the frail elderly, especially when complicated by dementia (Gott & Ingleton, 2011; NCPC, 2014). Although the chances of developing cancer increase with age and many very old people live, knowingly or unknowingly, with cancer along with multiple co-morbidities, most of those dying specifically of cancer are not the very old. Cancer patients are less likely to a) have multiple co-morbidities that may reduce their agency, b) have cognitive impairments such as dementia that reduce mental capacity to make informed choices, and c) be widowed, so they have spouses to help enact their choices. Informed decisions by those dying of cancer therefore stand the best chance of being both made and carried out.

The EOL Strategy nevertheless commits the National Health Service (NHS) to palliative care for all. Improving dying through open conversation and informed choice may or may not resonate so easily with the lived experience of frail, confused elderly patients (Pollock *et al.* 2014), but it clearly resonates with neo-liberal political agendas that have divided the NHS into internal markets in which both patients and healthcare providers exercise choice as to where and how care is bought (Conway, 2011). We have already noted that the Strategy is to offer *some* choices – *where* to die, but not *when* to die. Thus choices are not claimed by citizens, but ‘offered’ by those in power; citizens are required to make choices, even if their choice is not to choose (Armstrong, 1984) - all of which characterises neo-liberal governmentality (Arnason & Hafsteinsson, 2003; Borgstrom, 2014; Conway, 2011).

2) Compassion

Though discourses of compassionate care have been evident within the palliative care and hospice movements (Larkin, 2011), and also in Buddhist approaches to EOLC (Watts & Tomatsu, 2012), we focus on media and political discourses in England in the wake of successive scandals – outlined here – about the care of elderly and/or dying people. No sooner had the Strategy been published than

the British news media began highlighting a growing number of instances of appalling care for people near the end of life. These scandals revealed a lack of sensitivity to distress (Cole-King and Gilbert, 2011), and contributed to shifting public EOLC rhetoric towards compassion. The scandals concerned care homes, home care, and hospital care. In 2011, Southern Cross, the UK's largest provider of care homes, became insolvent, raising questions about the private sector's ability to provide consistent and reliable residential elder care (Scourfield, 2012; Lloyd *et al.*, 2014a). Despite the EOLC Strategy promoting dying at home, home care services commissioned by social services have suffered severe financial cuts, more so than the NHS, and were struggling (Sykes & Groom, 2011). Moreover, the Liverpool Care Pathway, a tool to manage the last few days of life promoted by the Strategy, was shown to be causing neglect in a series of stories by the *Daily Mail*;^{vi} the pathway was reviewed (Neuberger, 2013) and then scrapped (Leadership Alliance, 2014).

But it is the Mid-Staffordshire hospital scandal that escalated the compassion discourse. From 2005-2008, managerial targets and economic/political pressures at this hospital permeated interpersonal relationships, radically reducing the time staff had for personal care; hundreds of vulnerable patients, mainly elderly, died prematurely after suffering terrible standards of 'care'. In 2009, Sir Robert Francis was asked to chair an enquiry, which heard many stories of 'appalling care', and finally reported in 2013 (Francis, 2013). Collectively, these scandals represent the context in which compassion has sparked the public imagination, particularly in relation to the deaths of elderly persons.

The script of the Francis report and media coverage of these scandals was not that people were being denied choices at the end of life, but that in some organisations, finance and politics led to deficits of empathic care – *that* was why people were having such bad deaths, in such large numbers. The health ombudsman has also implicated lack of compassion, rather than lack of choice, in bad deaths (Abraham, 2011). In response, the Department of Health continues to explore how to ensure that all patients are treated with compassion and humanity.^{vii} Unlike the choice discourse which actively argues for a neo-liberal approach to care, 'compassion' is a defensive discourse,

reacting to market-oriented reforms of healthcare structures in an attempt to rescue socialised health and social care.^{viii}

Although these scandals are at first sight about compassion in nursing care, it soon becomes clear they are largely about lack of compassion for people, often frail and/or elderly, at the end of their lives. The scandals concern how elderly Britons today die and how they are cared for, or not cared for, in their final months. Yet, compassion is by no means a purely UK agenda. The Hearts In Healthcare campaign, for example, emanates from New Zealand (Youngson, 2010), while in recent years in the USA a discourse of (lack of) compassion has arisen in healthcare in general (Lown, Rosen, & Marttila, 2012) and within EOLC Schwartz rounds are a much-cited technique for advancing compassionate care.^{ix} The discourse of compassion therefore is used internationally to re-construct EOLC as a way of responding to presumed (unnecessary) suffering at the end of life.

Analysis

1) Choice

There is a considerable literature showing that individualist cultures value individual autonomy (Hofstede, 2001), and it is in this cultural context that personal autonomy, operationalised as informed choice, has grown over the past forty years to dominate western medical ethics (George & Harlow, 2011). By contrast, in collectivist cultures, relationships within the extended family are more highly valued than personal autonomy (Frey *et al.*, 2014). But even if patients operate within the cultural context of individual informed choice, the EOL choice agenda can still be problematic, as outlined in the following sections.

Who wants to choose?

We have already observed that in neo-liberal governance, citizens are required to be self-ruling, making informed choices which school, hospital or other services they or their children will utilise.

They are not given a choice not to choose (Giddens, 1991). It has been observed, however, that many Britons do not wish to choose which school to send their child to or which hospital to go to for an operation; they just want their local school or hospital to be really good (Wallace and Taylor-Gooby, 2010). In other words, they desire high standards and equal access. Choice can become a burden, not least as information is always incomplete, and weighing pros and cons (e.g., technical quality, general atmosphere, distance from home) is not an exact science (Salecl, 2010). Whether a person wishes to die at home may well depend in part on the quality of the alternatives, but few citizens have, or indeed can have, accurate knowledge of the quality of EOLC in the various local hospitals and care homes, especially – in the case of advance directives – months or years in advance. And when the time approaches, as a researcher commented about the situation in Sweden, 'The dying don't chose to choose, they choose to be...relieved of most responsibilities.'^x Some ethicists conclude that there is little empirical evidence to support this kind of choice discourse at the end of life (Drought & Koenig, 2002).

How people feel and act in the face of fateful moments – not just terminal illness or a fall that initiates terminal decline, but also failing a vital exam, a marriage not working out, an accident – that mark a crossroads in the individual's life are not easily accounted for in terms of either agency or structure (Hockey & James, 2003). Even people with agency and resources may, at such a crossroads, go with the flow rather than rationally evaluate options; the new direction may not be an autonomous choice, but not fatalism either. Rather, 'fate is met with suffering, resistance, coping, sense-making, haunting or escaping' (Bagnolia & Ketokivi, 2009, p. 317; Holland & Thompson, 2009). This is certainly the case at the end of life when the experience of dying shifts day by day, hour by hour, from positive to negative and back again (Kellehear, 2014). Choice, let alone 'autonomous informed choice', may be promoted by western medical ethics, but rarely fits lived reality at a crossroads (Borgstrom, 2014; Ellis, 2013).

On whose behalf?

In a respected British book on advance care planning, edited by Thomas and Lobo (2011), the assumed subject is a free, autonomous individual. The book includes just one dissenting contribution, arguing that from an individualist view,

‘expressions of ... my rights, needs, and wants are all that matter; whereas from the communitarian view, individual interests are freely subjugated according to the impact upon others’ personal rights and projects. The common good is what matters. We all live connected lives.’ (George and Harlow, 2011:59)

Even in individualistic societies, individuals can be concerned about the common good. Advance directives are often made not in terms of a person’s right to choose how to die, but in order to reduce suffering for their family. And as a recent report on EOLC states, 'When people consider their needs at the end of life, they are also concerned for their relatives and those who care for them.' (Henry, 2015, para 53). Not being ‘a burden’ on the rest of the family, according to another study, is a high priority for many people at the end of life (Waghorn, Young, & Davies, 2011); for example, a person’s choice about where to be cared for may reflect how they perceive their carers’ rather than their own needs (Borgstrom, 2014). This latter study of EOLC shows how patients make ‘choices’ as relational selves, often struggling to make these choices in the way health policy demands of them. In our later section on compassion, we explore further this relational understanding of humans, even those who live in historically individualistic cultures currently dominated by neo-liberal politics and economics.

How informed can EOL choices be?

As noted, the EOL choice agenda has been promoted by the palliative care lobby, whose experience is based largely on people dying in midlife or early old age (the so-called second and third ages). Currently, these age groups comprise baby boomers with typically consumerist values which are more or less congruent with neo-liberalism (Gilleard and Higgs, 2007). Making choices as one faces

dying of cancer in one's sixties or earlier seventies may be both realistic and welcomed. Yet, more people die of multiple infirmities, often with reduced mental capacity, in the rather older 'fourth age'. Gilleard and Higgs (2010) describe this as a 'black hole' from which no light escapes. Second and third agers being urged to make informed advance directives do not know what it would be like to have a stroke or to develop dementia; they cannot predict whether, when they become very, very old, they will tire of life or whether the urge to survive will continue to the very end.

Seale (1998) has offered a complementary image to the black hole, namely that of 'falling from culture'. People are born largely biological beings, but through socialisation become increasingly social and cultural beings; at the other end of life, slow dying can entail a social death, a loss of social identities as a person descends into just a body to be fed, watered and toileted (Twigg, 2006). Accordingly, advance care planning is – in theory if not in practice (Borgstrom, 2014) – a process, not a one-off, but even as people start to enter the fourth age of increasing dependency they typically resist identifying with it, positioning themselves within an active independent third age (Lloyd et al, 2014b).

A false promise?

We mention here just two, among many, reasons why it may not be possible to carry out EOL choices. Healthcare professionals' diagnosis of needs may not easily accommodate patients' wants. In the early 1990s, a Canadian study concluded that 'patient control over dying represents a challenge to the clinical judgement of health care professionals ...(and) to their professional autonomy and power' (Kelner & Bourgeault, 1993, p. 757). Since then, as the study predicted, healthcare practitioners have conceded some of their autonomy, and work more in partnership with patients in decision making, but the tension between clinical need and consumer choice remains.

Choices often cannot be enacted because resources and capabilities are limited. A person may wish to die in the local hospice, but no beds are available. Or they may wish to die in their residential care home, but when the final hours arrive the staff may not have the relevant EOLC skills so call an ambulance that leads to death in hospital. Or a person may wish to die in their own home, but their family carers may become too exhausted to fulfil their commitment. Stating a choice is one thing. The enactment of the choice depends on many other things, not least the resources of the person's social network and of local health and social care services.

Conclusion

In sum, as Britons near the end of their lives, meeting their fate in their own way, they are nevertheless required by the healthcare system to speak, to make choices that a) reflect a political agenda, b) are limited, both by resources and by the law, c) cannot be fully informed, and d) in any case may not be realisable. Healthcare professionals are caught between being required to inform and to record the patient's choices, and simply being with the person as they work out their own way. Patients are caught between making choices that can produce a tick in a bureaucratic box, and considering the needs of those around them in an ongoing conversation. Whilst still promoting patient choice at the end of life, the recent national review of choice in EOLC acknowledges these problems and contradictions in the choice discourse (Henry, 2015).

2) Compassion

We now move to the EOLC discourse about compassion, and the lack of it. We look briefly at policy, practice, and theory, questioning whether compassion as a relationship can be monetised or trained for.

Policy

According to Butler and Drakeford (2005, p.5), ‘scandals are the policy equivalent of the earthquake ... powerful signals that change is occurring, or that the pressure for change has reached unsustainable levels.’ Scandals are typically followed by official reports, public inquiries, and noble words, yet rarely lead to policy change that tackle the structural causes of what is wrong (Lloyd et al, 2014a).

The Francis Report was clear that compassionate care, in which patients come first, requires a culture change in many hospitals. Yet, developing a ‘a culture of compassionate care’ in nursing – defined by the 6 Cs of care, compassion, competence, communication, courage, and commitment (Commissioning Board Chief Nursing Officer and DH Chief Nursing Adviser, 2012) – affirms existing principles rather than new values and practices (Watterson, 2013). Francis was clear, however, that embedding a culture of compassion requires a financial and political transformation, and by February 2015 the government claimed that it funded more front-line staff and implemented a more robust inspection regime.^{xi} Nevertheless, Sir Robert Francis continues to consult with the public and healthcare workers about what is wrong with patient care, and the NHS compassionate care website is active. One insider reported the impact of the Francis inquiry as ‘seismic’^{xii}, though what, if any, change it actually leads to, other than rhetoric, only time will tell.

Practice

Many healthcare workers demonstrate acts of kindness every day. Healthcare scandals, however, can create an impression that many healthcare workers are heartless, thus undermining morale which has already been lowered by poor pay and conditions, and recurrent service re-organisations (Paley, 2014). Thus, many recognise that key to developing compassionate care is to value care staff and reduce burnout (e.g. Firth-Cozens and Cornwell 2009, McCloskey & Taggart, 2010). This is challenging because care work entails dirty manual labour cleaning up leaky bodies, which are experienced as polluting (Douglas, 2002; Lawton, 2000).

Validating care work is particularly problematic in England, however, because of the commodification of care. Care 'packages' are literally bought and sold. In state-funded care, the word 'care' is typically used not as an active verb ('I care for you'), but as an abstract noun, a package to be 'delivered' to 'service users'. Private agencies compete with one another for contracts to deliver care packages to vulnerable people at home, and to win contracts they must drive down pay and working conditions. The services the agency contracts to deliver to any one service user are defined as physical acts, such as bathing, cooking, feeding, toileting, shopping; the manner in which these acts are done is not accounted for. 'Presence' - sitting with the person, performing small personal acts of kindness (van Heijst, 2011) - falls outside the contract; in other words, compassion is not contracted for. Time management has split *caring for* and *caring about*, the former a legitimate part of a care package, the latter rarely so (Cohen, 2015). And yet, many carers find (often unpaid) time to be compassionate, to sit and chat with the service user, their emotional labour neither contractually recognised nor financially rewarded (Bolton & Wibberley, 2014; England & Dyck, 2011).

There is thus a contradiction between policy rhetoric about care being compassionate, and the reality of the commodification of care in which 'presence' is the one thing that cannot be commodified and contracted for – rather like in education, where inspirational teaching is the one thing that cannot be measured. There thus seems to be an irreconcilable conflict between the marketization of care, and developing a culture of compassionate care. For care to become compassionate within a market economy, two challenges need to be addressed. First, bodywork needs higher status. Second, care packages need to include time for 'presence' as well as time to do bodywork. In other words, *caring about*, as well as *caring for*, needs to be explicitly and financially recognised.

Theorising compassion

The right of individual patients to make informed choices about their care has been extensively theorised within medical ethics, particularly in relation to their best interests (Gillon, 2003). In this

section we indicate how compassion can be theorised. We focus on compassion as a relationship and quality of care, rather than public health approaches to EOLC that employ a similar language (Kellehear, 2005). Without discussion about what compassion is, the intentions behind the rhetoric risk being eclipsed in healthcare ethics by patient autonomy and the marketization of care.

Social solidarity provides one such basis for compassion in healthcare (Ignatieff, 1976). Ballatt and Campling (2011) observe that *kind* is etymologically related to *kin*. Compassion, feeling *with*, requires and/or promotes a sense of kinship - the sense of social solidarity, on which the NHS was founded. Richard Titmuss (1970) famously theorised this in his study of blood donation in which British citizens experience the NHS in terms of generalised reciprocity; receiving healthcare free at the point of need induces a desire by citizens to give something back. In so far as healthcare staff and patients still experience it this way, the NHS does not operate on market principles, even though its economic structure is being moved in that direction.

In the West, feminist ethics (Gilligan, 1982; Noddings, 1984) have challenged notions of the isolated, autonomous individual in favour of inter-dependence in which autonomy is 'achieved in and through relationships' (Lloyd, 2012, p. 4; Mackenzie & Stoljar, 2000), which has in turn inspired an ethics of care (Tronto, 1994), especially in the Netherlands (Mol, 2008; Olthuis, 2007; van Heijst, 2011; Verkerk, 2001). Feminist ethics do not support compassion as a one-way care relationship, as the concept has been used within the EOLC discourses above. In van Heijst's model of professional loving care (PLC), for example, the healthcare worker as well as the patient has needs that should be respected; PLC is not self-abnegation. Indeed, without a degree of reciprocity, without the carer's needs being recognised, and without finding meaning in the interaction, one-way compassion is likely to lead to burnout (e.g. Perry, 2008).

This raises the issue of dependency. The British disability lobby has vigorously challenged the concept of care because it connotes dependency and lack of autonomy, but Lloyd (2012, p. 37) argues that dependency is a problem only 'when seen in the context of a culture that regards independence as the norm'. What does care mean for someone who cannot reciprocate? This has

been explored theologically by Vanstone (1982), and empirically by the Japanese sociologist Yamazaki (2008). Yamazaki suggests that western palliative medicine's script for the good death condemns to a bad death those with 'no apparent awareness of dying and (who) cannot make autonomous decisions', i.e. those in coma or suffering from advanced dementia or a major stroke. Analysing one of Japan's many medical mangas (comic book stories), a genre which typically purveys ideals more than reality, he shows that Japan has a script for a good death in such cases, for 'living as a comatose patient still involves interactions and exchanges with both formal and informal carers'. Japan's relational self, though undermined by neo-liberal reforms, values empathetic reading/gauging of others in all social situations (Hendry, 2003), and in the story nurses gauge empathetically 'unvoiced needs, providing comfort without actually being asked.' (Yamazaki, 2008, p. 17). Thus compassion can be shown even for and by a patient who is unable to exercise choice and might be deemed in western ontology, socially dead.

Anglophone Western countries would not wish to emulate most aspects of Japanese EOLC (Long, 2005), and in any case, Japanese values cannot simply be imported into the West. But in western culture, intuiting others' needs – though not trumpeted by medical ethicists – is valued within nursing (Rew & Barrow, 2007). Recent critical British reports into elder care reveal how empathetic reading/gauging - of the most basic kind (e.g. the person needs help eating) - is often not done; even if individual professionals have compassionate intentions their behaviour may be non-helping (Paley, 2014). Relying overmuch on the principle of patient autonomy undermines relational care in those many situations where the patient has no agency to make their needs known. The more healthcare staff value communication with and from the patient and the more they value informed patient choice, the more likely they are to see patients who are physically or mentally incapable of communicating or making choices as socially dead (Sweeting & Gilhooly, 1991). A relational concept of self, however, allows for relationships by and with carers, delaying or mitigating social death (Lloyd, 2012). We therefore argue that both compassion and choice be embedded within an ethic of relationality.

Communitarian theories of solidarity (Jordan, 1989), relational theories of wellbeing favoured outside the Anglophone world (White, 2010), and feminist care ethics thus appear to offer a better basis than neo-liberalism for providing frail elderly patients with the EOLC they deserve. Yet, even if underplayed in medical ethics and undermined by NHS marketization, solidarity, kindness, and compassion exist in substantial measure in countries such as the UK and USA whose political elites embrace neo-liberal health policies. In collectivist societies that formally value relatedness, individuals do make choices for themselves even if the language to describe this is limited (Long, 2005). So too in individualistic societies, such as the USA (Bellah *et al.*, 1985), relationships, compassion and commitment to others are valued, even if the language for validating this is impoverished.

The choice discourse, though resonating with contemporary political culture and well-grounded in western medical ethics, becomes decreasingly appropriate as people's agency and capacity reduce toward the end of life. The compassion discourse shows the opposite strengths and weaknesses: it becomes increasingly appropriate the more the patient's agency declines, but does not easily fit contemporary political ideology and is less well elaborated in medical ethics. If our consideration of practice showed how the commodification of care undermines compassion, our consideration of theory suggests that neo-liberal assumptions about individuals with the right to make decisions about their own lives— while potentially enhancing care for patients with full agency — may undermine the possibilities of caring for those with reduced agency and capacity.

Conclusion

In the era following the Francis Report, policy actors in British healthcare increasingly understand that, for choices to be realisable, care needs to be integrated, competent, confident, compassionate, and resourced (NCPC, 2014). In February 2015, *The Choice in End of Life Care Review Board*, mandated by the government 'to consider how the quality and experience of care for adults at the

end of life and those close to them could be improved by expanding choice', published its report. The report makes very clear that offers of 'choice' are vacuous in the absence of widespread, high quality, co-ordinated care – precisely the points made in this article. Many of the patients whom the board consulted were exercised more about the variability of the quality of care than their right to make choices. The report is clear that 'good care necessarily involves choice and choice is valuable only when there is a foundation of good care' (Henry, 2015, para 43). If more choice is no solution to a compassion deficit, the report argues that skilled, compassionate care will help solve a choice deficit. The review board has turned a neo-liberal mandate to increase choice into a critique of health and care inequalities; the political response to the report remains to be seen.

We welcome the report's bringing together of two discourses – choice and compassion – that had got separated in public EOL debate in England 2008-2014, and we would like to share the review board's hope that patient choice and equitable provision of compassionate skilled care can be mutually reinforcing. This article, however, has indicated several ways in which choice and compassionate care are not as close kin as might be hoped; these need to be reflected on if care and choice, even if not close relatives, are to co-operate as friends. Choice and compassion have different origins in contemporary EOLC discourses: 'choice' as an offensive within the campaign to neo-liberalise healthcare, 'compassion' as a defensive reaction to scandal. Each faces limits and challenges when it comes to caring for the majority of the dying, that is, those in old age – choice becomes a tick box, compassion a commodity. Choice at the end of a very long life may be limited by the person's body and mind, by family relationships, and by healthcare bureaucracies whose workings are opaque to patients and even to those working within them. At the same time, compassion in care is undermined by the commodification of *caring for* and the neglect of *caring about* that, in the absence of evidence to the contrary, appears to be inherent in marketization.

References

- Abraham, A. (Ed.). (2011). *Care and compassion?* Health Service Ombudsman.
- Armstrong, D. (1984). The Patient's View. *Soc.Sci.Med*, 18(9), 737-744.
- Armstrong, D. (1987). Silence and Truth in Death and Dying. *Soc.Sci.Med*, 24(8), 651-657.
- Arnason, A., & Hafsteinsson, S. B. (2003). The revival of death: expression, expertise and governmentality. *British Journal of Sociology*, 54(1), 43-62.
- Attig, T., & Stillion, J. (Eds.). (2015). *Death, Dying and Bereavement: Contemporary Perspectives, Institutions and Practices*. New York: Springer.
- Bagnolia, A., & Ketokivi, K. (2009). At a crossroads: contemporary lives between fate and choice. *European Societies*, 11(3), 315-324.
- Ballatt, J., & Campling, P. (2011). *Intelligent Kindness: Reforming the Culture of Healthcare*. London: Royal College of Psychiatrists.
- Bellah, R., Madsen, R., Sullivan, W. M., Swidler, A., & Tipton, S. M. (1985). *Habits of the Heart: Individualism and commitment in American life*. Berkeley: University of California Press.
- Bolton, S. C., & Wibberley, G. (2014). Domiciliary care: the formal and informal labour process. *Sociology*, 48(4), 682-697.
- 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., Barclay, S., & Cohn, S. (2013). Constructing denial as a disease object: Accounts by medical students meeting dying patients. *Sociology of Health and Illness*, 35(3), 391-404.
- Butler, I. and M. Drakeford (2005). *Scandal, Social Policy and Social Welfare*. Bristol, Policy Press.
- Cohen, R. L. (2015). Crises in care - compassion and body work. *Discover Society*, Jan 3 2015(<http://www.discoversociety.org/2015/01/03/crises-in-care-compassion-and-body-work/>). Last accessed 13 March 2015.
- Cole-King, A. and P. Gilbert. 2011. Compassionate Care: The Theory and The Reality. *Journal of Holistic Healthcare*, 8(3):29-35

- Commissioning Board Chief Nursing Officer and DH Chief Nursing Adviser. (2012). *Compassion in practice. Nursing, midwifery and care staff: our vision and strategy*. London: NHS Dept of Health.
- Commonwealth of Australia. (2010). *Supporting Australians to Live Well at the End of Life: National Palliative Care Strategy*.
- Conway, S. (Ed.). (2011). *Governing Death and Loss: Empowerment, Involvement and Participation*. Oxford: Oxford University Press.
- DH: Department of Health. (2008) *The End of Life Care Strategy*. Department of Health: London
- Douglas, M. (2002). *Purity and Danger*. London: Routledge.
- Drought, T. S., & Koenig, B. A. (2002). "Choice" in End-of-Life Decision Making: Researching Fact or Fiction? *The Gerontologist*, 42(Supplement 3), 114–128.
- Economist Intelligence Unit. (2010). *The quality of death: ranking end-of-life care across the world* .
- Ellis, J. (2013). "Thinking beyond rupture: continuity and relationality in everyday illness and dying experience." *Mortality*, 18(3): 251-269.
- England, K., & Dyck, I. (2011). Managing the body work of home care. In J. Twigg (Ed.), *Boy work in health and social care* (pp. 36-49). Chichester: Wiley-Blackwell.
- Firth-Cozens, J. and J. Cornwell. 2009. *The Point of Care: Enabling Compassionate Care in Acute Hospital Settings*. London: King's Fund
- Francis, R. (2013). *The Mid Staffordshire NHS Foundation Trust Public Inquiry: Final Report*. London: The Stationery Office.
- Frey, R., Raphael, D., Bellamy, G., & Gott, M. (2014). Advance care planning for Maori, Pacific and Asian people: the views of New Zealand health care professionals. *Health & Social Care in the Community*, 22(3), 290-299.

- George, R and T. Harlow (2011). Advance care planning: politically correct, but ethically sound? In Thomas, K. and B. Lobo, Eds. (2011). *Advance Care Planning in End of Life Care*. Oxford, Oxford University Press. pp. 55-72
- Giddens, A. (1991). *Modernity and Self-Identity*. Stanford, Stanford University Press.
- Gilleard, C., & Higgs, P. (2007). The third age and the baby boomers: two approaches to the social structuring of later life. *International Journal of Aging and Later Life*, 2(2), 13-30.
- Gilleard, C., & Higgs, P. (2010). Aging without agency: theorizing the fourth age. *Aging & Mental Health*, 14(2), 121-128.
- Gilligan, C. (1982). *In a Different Voice: psychological theory and women's development*. Cambridge MA: Harvard University Press.
- Gillon, R. (2003). Ethics needs principles--four can encompass the rest--and respect for autonomy should be "first among equals." *Journal of Medical Ethics*, 29(5), 307-312.
- Gott, M., & Ingleton, C. (Eds.). (2011). *Living with Ageing and Dying: Palliative and End of Life Care for Older People* Oxford: Oxford University Press.
- Green, J. W. (2008). *Beyond the Good Death: The Anthropology of Modern Dying*. Philadelphia: University of Pennsylvania Press.
- Hendry, J. (2003). *Understanding Japanese society*. London: Routledge.
- Henry, C. (2015). *What's important to me: A Review of Choice in End of Life Care*: The Choice in End of Life Care Programme Board.
- Hockey, J., & James, A. (2003). *Social Identities Across the Life Course*. New York: Palgrave Macmillan.
- Hofstede, G. (2001). *Culture's Consequences: Comparing Values, Behaviours, Institutions and Organizations across Nations*. Thousand Oaks: Sage.
- Holland, J., & Thompson, R. (2009). Gaining perspective on choice and fate: revisiting critical moments. *European Societies*, 11(3), 451-469.
- Ignatieff, M. (1976). *The Needs of Strangers*. London: Hogarth Press.

- Jordan, B. (1989). *The common good: citizenship, morality and self-interest*. Oxford: Blackwell.
- Kellehear, A. (1984). Are we a death-denying society? A sociological review. *Social Science & Medicine*, 18(9), 713-723.
- Kellehear, A. (2005). *Compassionate Cities: Public Health and End of Life Care*. New York: Routledge.
- Kellehear, A. (2014). *The Inner Life of the Dying Person*. New York: Columbia University Press.
- Kelner, M. J., & Bourgeault, I. L. (1993). Patient control over dying: Responses of health care professionals. *Social Science and Medicine*, 36(6), 757-765.
- Larkin, P. (2011). Compassion: the essence of end-of-life care. In I. Renzenbrink (Ed.), *Caregiver Stress and Staff Support in Illness, Dying and Bereavement* (pp. 154–169). Oxford: Oxford University Press.
- Lawton, J. (2000). *The dying process*. London: Routledge.
- Leadership Alliance for the Care of Dying People. (2014). *One Chance to Get It Right: Improving People's Experience of Care in the Last Few Days and Hours of Life*.
- Lloyd, L. (2004). Mortality and morality: ageing and the ethics of care. *Ageing and Society*, 24(2), 235–256.
- Lloyd, L. (2012). *Health and care in ageing societies: A new international approach*. Bristol: Policy Press.
- Lloyd, L., Banerjee, A., Jacobsen, F.F., Harrington, C., and Szehebely, M. (2014a). "It's a Scandal!: Comparing the causes and consequences of nursing home media scandals in five countries." *International Journal of Sociology and Social Policy*, 34: 2-18.
- Lloyd, L., Calnan, M., Cameron, A. M., Seymour, J., & Smith, R. (2014b). Identity in the fourth age: perseverance, adaptation and maintaining dignity. *Ageing & Society*, 34(1), 1-19.
- Lofland, L. (1978). *The Craft of Dying: the modern face of death*. Beverly Hills: Sage.
- Long, S. O. (2005). *Final Days: Japanese culture and choice at the end of life*. Honolulu: University of Hawaii Press.

- Lown, B. A., Rosen, J., & Marttila, J. (2012). An Agenda For Improving Compassionate Care: A Survey Shows About Half Of Patients Say Such Care Is Missing. *Health Affairs*, 30(9), 1772-1778.
- Lynn, J., & Adamson, D. M. (2003). *Living well at the end of life: adapting health care to serious chronic illness in old age*. Santa Monica, CA: Rand.
- Mackenzie, C., & Stoljar, N. (Eds.). (2000). *Relational Agency: Feminist Perspectives on Autonomy, Agency, and the Social Self*. Oxford: Oxford University Press.
- McCloskey, S., & Taggart, L. (2010). How much compassion have I left? An exploration of occupational stress among children's palliative care nurses. *International Journal of Palliative Nursing*, 16(5), 233-40.
- Minister of Health. (2007). *Canadian strategy on palliative and end-of-life care*. Ottawa: Health Canada.
- Ministry of Health. (2001). *The New Zealand Palliative Care Strategy*. Wellington.
- Mol, A. (2008). *The Logic of Care: Health and the problem of patient choice*. London: Routledge.
- Moorhouse, P., & Mallery, L. (2010). PATH: a new approach to end-of-life care. *The Canadian Review of Alzheimer's Disease and Other Dementias*.
- Murray, S. A., Kendall, M., Boyd, K., & Sheikh, A. (2005). Illness trajectories and palliative care. *British Medical Journal*, 330, 1007-1011.
- NCPC. (2014). *The end of life care strategy: new ambitions*. London: National Council for Palliative Care.
- Neuberger, J. (2013). More Care, Less Pathway: a review of the Liverpool Care Pathway. from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf
- Noddings, N. (1984). *Caring: A feminine approach to ethics and moral education*. Berkeley: University of California Press.
- Olthuis, G. (2007). *Who cares? an ethical study of the moral attitude of professionals in palliative care practice*. Radboud University, unpublished PhD thesis.

- Paley, J. (2014). Cognition and the compassion deficit: the social psychology of helping behaviour in nursing. *Nursing Philosophy : An International Journal for Healthcare Professionals*, 15(4), 274–87.
- Perry, B. (2008). Why exemplary oncology nurses seem to avoid compassion fatigue. *Canadian Oncology Nursing Journal = Revue Canadienne de Nursing Oncologique*, 18(2), 87–99.
- Pollock, K., Caswell, G., Harwood, R., & Porock, D. (2014). Caring for frail or seriously ill older people dying on acute hospital wards. *BMJ Supportive & Palliative Care*, 4(A20).
- Rew, L., & Barrow, E. (2007). Intuition in nursing, a generation in studying the phenomenon. *Advances in Nursing Science*, 30(1), e15–e25.
- Salecl, R. (2010). *Choice*. London: Profile Books.
- Scourfield, P. (2012). "Cartelization revisited and the lessons of Southern Cross." *Critical Social Policy*, 32(1): 137-148.
- Seale, C. (1998). *Constructing death: the sociology of dying and bereavement*. Cambridge: Cambridge University Press.
- Seymour, J. (2012). Looking back, looking forward: the evolution of palliative and end-of-life care in England. *Mortality*, 17(1), 1-17.
- Sykes, W., & Groom, C. (2011). *Older people's experiences of home care in England*. Manchester.
- Sweeting, H., & Gilhooly, M. (1991). Doctor, Am I Dead? A review of social death in modern societies. *Omega*, 24(4), 251-269.
- Titmuss, R. M. (1970). *The gift relationship : from human blood to social policy*. London: Allen & Unwin.
- Tronto, J. C. (1994). *Moral boundaries: a political argument for an ethic of care*. London: Routledge.
- Twigg, J. (2006). *The body in health and social care*. Basingstoke: Palgrave Macmillan.
- van Heijst, A. (2011). *Professional loving care: an ethical view of the health care sector*. Leuven: Peeters.
- Vanstone, W. H. (1982). *The Stature of Waiting*. London: Darton, Longman, Todd.

- Verkerk, M. (2001). The care perspective and autonomy. *Medicine, Health Care and Philosophy*, 4(3), 289-294.
- Waghorn, M., Young, H., & Davies, A. (2011). Opinions of patients with cancer on the relative importance of place of death in the context of a "good death." *BMJ Supportive & Palliative Care*, 1(3), 310–314.
- Wallace, A. and P. Taylor-Gooby (2010). "New labour and reform of the English NHS: user views and attitudes." *Health Expectations*, 13(2): 208-217.
- Walter, T. (1994). *The Revival of Death*. London: Routledge.
- Watterson, L. (2013). 6Cs + Principles = Care *Nursing Standard*, 27(46), 24-25.
- Watts, J., & Tomatsu, Y. (Eds.). (2012). *Buddhist Care for the Dying and Bereaved*. Somerville, MA: Wisdom Publications.
- White, S. (2010). Analysing wellbeing: a framework for development policy and practice. *Development in Practice*, 2(2), 158-172.
- Yamazaki, H. (2008). *Rethinking good death: insights from a case analysis of a Japanese medical comic*. University of Oxford: Uehiro-Carnegie-Oxford Conference on Medical Ethics, 11-12 Dec.
- Youngson, R. (2010). Taking off the armor. *Illness, Crisis & Loss*, 18(1), 79-82.
- Zimmermann, C. (2004). Denial of impending death: a discourse analysis of the palliative care literature. *Social Science and Medicine*, 59(8), 1769-1780.

ⁱ E.g. in the USA <https://www.compassionandchoices.org/>

ⁱⁱ E.g. in the UK <http://compassionindying.org.uk>

ⁱⁱⁱ Borgstrom submitted documents as part of the public and professional consultation for this review.

^{iv} This is evidence by the annual International Advance Care Planning conference which travels the world. In 2015 it will be held in Germany. See <http://acpelsociety.com/>

^v <http://dyingmatters.org/>. In the USA, there is the similar, though more unofficial, Conversation Project <http://theconversationproject.org/>.

^{vi} The Daily Mail is a conservative British daily newspaper. The paper reported that its campaign against the Liverpool Care Pathway was vindicated: <http://www.dailymail.co.uk/news/article-2364783/Death-path-way-damned-Mail-campaign-vindicated-devastating-report-scandal-end-life-treatment.html>. Accessed 5 March 2015.

^{vii} <http://compassionatecare.dh.gov.uk/>

^{viii} Compassion scandals can be used to undermine confidence in socialised medicine, as in the USA around the medical care provided to veterans (e.g. Krugman, P. (2006, January 27). Health Care Confidential. *The New York Times*. Retrieved from <http://query.nytimes.com/gst/fullpage.html?res=9D0DE6DD113FF934A15752C0A9609C8B63>).

^{ix} <http://www.theschwartzcenter.org/>

^x Adela Toplean, 12 Sept 2013

^{xi} Progress Overview: 2 years since Francis. <http://compassionatecare.dh.gov.uk/2015/02/06/progress-overview-2-years-since-francis/> Accessed 27 Feb 2015.

^{xii} <http://compassionatecare.dh.gov.uk/2014/02/26/one-year-on/> Accessed 26 Feb 2014