



# Choice and compassion at the end of life: A critical analysis of recent English policy discourse



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## 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.

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## 1. 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 and 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 countries,<sup>1</sup> when promoting advance directives,<sup>2</sup> 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 2008–2014; 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 (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

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<sup>1</sup> E.g. in the USA <https://www.compassionandchoices.org/>.

<sup>2</sup> E.g. in the UK <http://compassionindying.org.uk>.

compassionate care, and by 2015 it was officially acknowledged that universally available high quality care is necessary for patient 'choice' to be meaningful (Henry, 2015).<sup>3</sup>

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.

## 2. History

### 2.1. 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.<sup>4</sup> 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.<sup>5</sup> 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 and 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 et al., 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 et al., 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 and 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

<sup>3</sup> Borgstrom submitted documents as part of the public and professional consultation for this review.

<sup>4</sup> 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/>.

<sup>5</sup> <http://dyingmatters.org/>. In the USA, there is the similar, though more unofficial, Conversation Project <http://theconversationproject.org/>.

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