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Policy

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National End-of-Life Care Policy in the English Context: The Problem and Solution to Death and Dying

Introduction

The End of Life Care Strategy (EOLCS) was released by the Department of Health (DH) in July 2008 to promote and reform the way dying persons are cared for by focusing on patient needs and preferences (DH, 2008b).[i] The policy is considered the first of its kind, both nationally and internationally, for systematically addressing end-of-life care (EOLC) in a way that is not intended to be disease-focused, using an integrated framework for the managed care of the dying via the EOLC pathway outlined in the document. The EOLCS draws on a history of palliative and hospice care within the United Kingdom (Seymour, 2012; and Ellis et al. in this volume) and is one of the reasons the UK is considered to be world-leading in end-of-life care provision (EIU, 2010). This chapter builds on the previous chapter by describing the discourses used within this policy arena to frame death and dying as a problem that can be solved through the implementation of EOLC within a neoliberal, and yet nationally funded health service, framework.

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). This chapter is based on an analysis of the EOLCS, related policy documents and events that

promoted implementation of the EOLCS. Initial analysis was part of a larger study about choice in EOLC (Borgstrom, 2014); this chapter reflects an up-to-date analysis of English EOLC policy discourse. Policy documents – like the EOLCS – are illustrations of organisational 'thinking activity' (Bellier, 2005, p243) that demonstrate the particular issues and values that gain prominence. They also are programmes for action and 'elicit particular kinds of responses' (Riles, 2006, p22). The purpose of this analysis is to make explicit the language and logics used within policy to justify EOLC – as the managed care of the dying – as an appropriate response to death as a contemporary social problem. By focusing on the rhetoric and discourses within policy that are used to legitimate and encourage the translation of policy into practice, it is possible to demonstrate the ways in which language constructs and organises reality (Foucault, 1977; Tonkiss, 1998). This is important given that it is argued in this chapter that the way policy positions death as a problem, and the solution it proposes in the form of EOLC, shapes the way dying can be experienced and how the notion of 'end of life' aligns with a neoliberal understanding of how health matters more broadly are to be managed.

This chapter summarises the discourses embedded in EOLC policy to reframe how death is currently understood and to be managed. Firstly, it describes the EOLCS and its mission. Secondly, the discourses within EOLC policy that position death and dying as a social and political problem are outlined, such as the university of death to justify the need for governmental policy. The chapter then goes on to explore how this policy broadly fits within the current political healthcare context. Whilst the examples drawn on in this chapter are from the English context, the language and logic used in the policy – and the subsequent changes that have occurred in healthcare practice –

can be observed in other Anglophone and Western contexts as death is framed as a both an individual experience and socio-medical problem.

End of Life Care Strategy

The EOLCS sees end-of-life care as the holistic care of people, irrespective of diagnosis or age, as they approach the end of their lives. There are three underlying assumptions about death and dying within EOLC policy: 1) that as people die, they have needs; 2) that dying, and therefore these needs, can be anticipated and planned for; and 3) if these needs are not met, people cannot experience a 'good death'. It is assumed that most people will want to be engaged in a process of advance care planning, which addresses this needs-based approach. These needs are largely framed within the biomedical and palliative care discourse of bodily decline and total pain, which can include 'supportive needs' (Saunders, 2006). This approach presumes people will require medical care as they die thereby medicalising death (Seymour, 1999). Whilst the next section outlines more generally how dying and death are framed as particular problems to be addressed by EOLC policy, this section outlines how the EOLCS was developed and implemented, reflecting the assumptions about death described here. It is important to note here that EOLC policy and related practices is one of many ways of dealing with death and dying in society; other chapters in this book address some of the alternatives (for example, see Richards, Chapter 4 in this volume, for a discussion of euthanasia).

Developing the Strategy

The EOLCS plays a large part in the UK's ranking as a world-leader of end-of-life care (EIU, 2010); the term strategy refers both to the document (DH, 2008b) and to

the policies set out in the EOLCS document. Growing out of the NHS Next Stage Review (House of Commons Health Committe, 2008), disease-specific frameworks (e.g. DH, 2001), and work done by the relatively new National End of Life Care Programme (NEOLCP)[ii], the strategy was developed within the DH. Its development was overseen by an advisory board that was chaired by Mike Richards (the then National Cancer Director), and supported by working groups focusing on particular elements of the policy, such as the workforce development (DH, 2008b, p34). Members of both the advisory board and working groups, whom are referred to in this chapter as policymakers, were primarily not civil servants and came from diverse professional backgrounds[iii], including chief executives of national charities and those with professional and/or personal experience in palliative and end-of-life care. These policymakers worked closely with the National Council for Palliative Care (NCPC)[iv] and the then NEOLCP, organisations that gathered examples of 'innovation' or 'best practice' and later actively promoted the EOLCS within the NHS and publically. To inform the content of the policy, consultations were also held with faith groups, carers' organisations, and researchers; at multiple points within the EOLCS and at events promoting the policies, the processes through which the EOLCS was developed were stressed as being systematic, inclusive and grounded in experience. Additionally, case studies of best practice and personal accounts wereused within the EOLCS (e.g. Box 7 provides an example of using the Preferred Priorities for Care document)[v] to demonstrate the evidence-base of the strategy[vi], how it addresses patient and professional concerns, and the potential positive impact of implementing the policy recommendations. Overall, the development of the EOLCS demonstrates what, at the time of its inception and creation, leading practitioners and consulted stakeholders felt was possible to achieve with the political and healthcare framework.

Implementing the Strategy

The overarching goal of the EOLCS is that all adults in England will have access to high quality of care at the end of their live, through the provision of more choice about where they are cared for and die (DH, 2008d). In a publication interpreting the importance of the EOLCS for patients and carers (DH, 2008f), the following implications were stated:

1) People would have the opportunity to discussion needs and preferences with professionals, and for these to be recorded and accommodated where possible;

2) Care and support will be coordinated and needs met;

3) People will have rapid access to specialist services and clinical assessment, wherever they are;

4) People will have high quality care during the last days of life;

5) People will be treated with dignity and respect.

Overall, people identified as being near the end of life would receive supportive, and clinically appropriate, care that is in line with their personal preferences irrespective of where they are being cared for or the time that needs arise. Drawing on hospice philosophy, this model of EOLC is holistic and addresses physical, social, psychological, and spiritual needs (McEvoy and Duffy, 2008). Additionally, the needs of carers are to be supported and bereavement care is considered an aspect of EOLC. These elements reflect the different stages of the EOLC pathway (Hayes et al., 2014) and hinge on patients being identified as approaching the end of their lives.[vii] Consequently, the EOLCS suggests that death is something that can be both foreseen and managed.

Ultimately, it was hoped that the implementation of the strategy would 'enhance choice, quality, equality and value for money' (DH, 2008b, p33) and allow people to have 'good deaths'. Good death is understood within the EOLCS as being without pain or other symptoms, being treated as an individual, being in familiar surroundings, and being in the company of close family and/or friends (DH, 2008b, p9).[viii] To achieve this, the EOLCS called for a system-wide change in how people are cared for towards and at the end of life as well as promoting a cultural change in how death and dying are discussed and viewed within society more generally. There was a multi-pronged approach to this policy implementation:

1) raise awareness of the EOLCS through roadshow events, aimed primarily at health and social care providers and commissioners, including presentations by Mike Richards (Richards, 2008);

2) adoption and monitoring of the EOLC pathway and related clinical tools in practice across healthcare sectors to promote both early identification of patients likely to be dying and facilitated advance care planning around patient needs and preferences. Practical advice was provided at events and newsletters promoting the EOLCS as well as a recent book (Hayes et al., 2014); the National End of Life Care Intelligence Network (NEOLCIN) was established to collect and analyse data and research relating to EOLC[ix];

3) increased health and social care professionals' education about EOLC, such as the 'Working together to improve end of life care' training pack[x] and e-learning about EOLC[xi];

4) increased healthcare spending for EOLC and reviews on joint-care spending (Hughes-Hallett et al., 2011; NHS England, 2014b). For example, the press release accompanying the EOLCS promised £268m for palliative care (DH, 2008a), a doubling in the 'investment' in palliative care (Richards, 2008:26);

5) improve the visibility and 'change attitudes to death and dying in society' (DH, 2008b, p11) by launching a social media campaign known as Dying Matters.[xii]

Four annual reviews have been published marking the progress made with implementing the EOLCS (DH, 2009, 2010, 2011, 2012). The EOLCS has been commended for making considerable changes to the management of dying and the experiences of end of life care, whilst its implementation has highlighted further areas of concern (NHS England, 2014a). For example, across the country, the numbers of people dying in their preferred place of death has increased[xiii] and there has been a year-on-year decrease in the percentage of people dying in hospital (DH, 2012). Whilst there has been some improvement for non-cancer-related patient care, there is still considerable inequality based on diagnosis (NEOLCIN, 2013), and it is likely that more research and service innovation will occur around end-of-life care, dementia, and frailty (see chapter 2 in this volume). Despite a policy-push for more people to die at home, the VOICES survey of bereaved suggests that pain management is worse in the home environment (ONS, 2014). The quality standard for EOLC produced by NICE (2011) continues to be the basis of monitoring and commissioning care, and additional recommendations have been made based on independent reviews (see section below on the tensions).

Death and Dying as a Contemporary Problems

End-of-life care is a particular way of dealing with dying, by anticipating and planning for future care needs. It is a relatively new field that cuts across disciplines and structural boundaries of health and social care (Seymour, 2012). In order to understand how EOLC is considered a legitimate approach for health policy, this section outlines the ways in which death and dying are discussed within EOLC policy that frame them as contemporary social problems. In doing so, I argue that these discourses set up EOLC as the solution to these problems by highlighting the potential role of advance care planning for changing the current experiences and patters of dying and death.

Changing Nature of Dying and Death

Demographic shifts, in terms of the number and kinds of death and the attributes of people who will be dying, are used within EOLC policy to provide a sense of urgency. For example, the executive summary to the EOLCS opens with the following statement:

> Around half a million people die in England each year, of whom almost two thirds are aged over 75. The large majority of deaths … follow a period of chronic illness such as heart disease, cancer, stroke, chronic respiratory disease, neurological disease or dementia. (DH, 2008c, p1)

Additionally, the EOLCS draws on research that estimates that death rates will rise (Gomes and Higginson, 2008). This is often referred to as the 'demographic ticking time bomb' facing the country[xiv] and is attributed to an ageing population (Vincent et

al., 2006). The use of such statistics and language situates EOLC policy in a rapidly changing social context, and implies that the previous political and medical ways of responding to death may no longer be appropriate. The logic used within the EOLCS is that due to the chronicity of diseases – and therefore 'expectedness' of death (NHS England, 2014a) – there is potential for more advance care planning to happen. Therefore, the EOLCS not only highlights why death and dying present a problem to society now (in terms of the changes resulting in more deaths), but also how the kinds of deaths (resulting from long-term illness, some which may challenge a person's capacity) are suitable for policy initiatives around managed dying.

Inequitable Access to Palliative and End-of-Life Care Services

There are two main issues about equity of EOLC addressed by the EOLCS: access to specialist services based on diagnosis and differences in care across health and social care settings. This inequality is problematic because the NHS is supposed to be a socially just system (DH, 2003). The recent priority setting in EOLC suggests that inequality in terms of access to care across time and space remains a core issue to be explored in EOLC research, practice and policy (James Lind Alliance, 2015). By acknowledging that 'for far too long the NHS had regarded specialist palliative care as an optional extra … [relying] too heavily on upon the goodwill and funding of charities' (DH, 2008b:31), the EOLCS is positioned as a way to promote and 'extend this quality of care … to all people who are approaching the end of life' (DH, 2008:30). An *Equality Impact Assessment* was published alongside the EOLCS addressing additional issues of affecting access and EOLC such as gender and sexuality, ethnicity and age (DH, 2008c).

Prior to 2008, EOLC in England was typically limited to specialist and/or voluntary

centres, like hospices. Whilst this care was generally positively regarded (Richards,

2008) it was also unintentionally inequitable due to issues of access based on disease-

type and progression (see chapter 2 in this volume). Patients who were recognised as

having a terminal condition were considered to have palliative care needs (Franks et

al., 2000) and treatment was often restricted to patients with relatively short-term

prognoses caused by cancer and some degenerative diseases like motor-neurone

disease (Field and Addington-Hall, 1999). Consequently, people who may have had

EOLC needs were not receiving palliative or end-of-life care, and recent research

suggests that there is still considerable variation in access to services (Dixon et al.,

2015).

In the EOLCS, it is noted that where a death occurs can affect how the death is

experienced and the kind of care given. For example, when launching the EOLCS

Mike Richards noted how hospices are 'beacons of excellence' and hospitals are often

considered as sites of 'inappropriate [too much medical] intervention' (Richards,

2008). Similar sentiments can be found in a report aimed at nurses, which noted that

up to '40% of patients who died in hospital did not have medical needs that required

them to be in an acute setting', describing this as 'not only expensive' but as

'inappropriate' and 'preventable' (Fenton and Maher, 2010, p7). In this discourse, the

setting of death is linked to the type and extent of (medical) intervention, implicitly

suggesting that deaths following intensive intervention (when death is a foreseeable

and expected outcome) are 'bad'.[xv] The EOLCS consequently promotes reducing the

amount of deaths occurring in hospital settings and an increase in deaths occurring at

home (Barclay and Arthur, 2008), as well as advance care planning that involves advance decisions to refuse treatments (DH, 2008b, p53-54).

Place of Death

Within the EOLCS it is claimed that it is 'distressing' that people are treated without dignity and respect and are unable to die where they wish (DH, 2008b, p9), which is often the result of a lack of symptom control, poor support for carers, and/or inequitable access to specialist services (Richards, 2008). The first page of the executive summary to the EOLCS highlights the variability of where people die: ranging from 58% of people dying in hospitals, to 18% dying in their own homes, to 4% dying in hospices (DH, 2008d, p1).These figures vary considerably across regions and this variation is regarded within the document as not reflecting a variation in the needs of the populations but rather a variation in service provision (DH, 2008b, p26). Where people die is often compared to where people would like to die: surveys of the general public suggest that between 56% and 74% to of people wish to die at home (National Audit Office, 2008). Influenced by the language and logic of the EOLCS, in 2010, following a report by Demos highlighting this disparity (Leadbeater and Garber, 2010) the BBC reported that people were 'denied die at home wish' (BBC, 2010). To support the premise that advance care planning will improve the experiences and care of dying persons, policy discourse frames this mismatch between preferred and actual place of death as problematic.

Death as a Social Issue

The universal nature of death is frequently used within EOLC policy discourse to justify the need for EOLC policy and a more 'open' approach to death within society.

In a publically-available internal document that outlines the potential impacts of the EOLCS for the DH, the need for the strategy is justified by the statement that 'everyone eventually dies, and many people are affected by, and need support during the illness and death of a loved one' (DH, 2008e, p1). More recently, a policy document bluntly stated that 'death is an inevitable part of life' (NHS England, 2014a, p23). Death is therefore projected as something that affects everyone and because of this universality, has a legitimate claim to being a subject of government policy. In terms of positioning the issues as important for health and social care, the EOLCS states that:

> how we care for the dying is an indicator of how we care for all sick and
> vulnerable people. It is a measure of society as a whole and it is a litmus test
> for health and social care services (DH, 2008d, p2).

Seymour interprets the EOLCS as responding to public scandals about care of the elderly (Seymour, 2012) and within the EOLCS, the phrase 'dignity and respect' is used eight times. More recent policy continues this logic, and addresses newer cases such as the Mid-Staffordshire scandal (Francis, 2013) and review of the Liverpool Care Pathway (as discussed below), by referring to a need for more compassionate care and the 'one chance' there is to make sure people have a good death (Leadership Alliance for the Care of Dying People, 2014). Consequently, the ways in which dying is experienced are a matter of social interest and political policy.

Despite this universality of death and publically-debated scandals, the Dying Matters Coalition argues that a societal taboo surrounds death, resulting in many people being

unable to experience the death they would like to or experiencing complicated grief (Seymour et al., 2010). This silence is presumed to extend to the medical profession, reflecting Glaser and Stauss' work on awareness contexts (Glaser and Strauss, 1965). For example, (parts of) the medical profession are claimed to view 'death as a failure' (Richards 2008). Within policy documents, this stance is interpreted as a potential cause of denial, which can have 'a detrimental impact on the extent to which people's preferences for care are elicited and their needs planned for' (DH, 2008e, p1). Therefore, a key element of the EOLCS is to encourage more discussion around death and dying, both publically, and within medical and social care, through activities like advance care planning (Thomas and Lobo, 2011). As epitomised in the catch phrase used by the Dying Matters Coalition – 'dying matters: let's talk about it' – the logic is that since death is universal and cannot be escaped, people should face up to it and talk about it, which can make the experiences of death and dying *better*.

Tensions Arising from EOLC Policy and Practice post-2008

Whilst the EOLCS was greeted as providing a positive vision for the future (Riley, 2008), it has also faced criticism. In particular, there are concerns about the role of choice (Randall and Downie, 2010) and how standards and tools – such as the Liverpool Care Pathway – have been implemented. This section highlights some of the tensions faced by the EOLCS, situating these within a neoliberal and changing healthcare context. The last element describes the future development of EOLC policy and practice more generally, which seeks to address these tensions.

Choice

A core feature of EOLC policy rhetoric and a defining feature of the EOLCS is the role of patient choice (Borgstrom, 2014). This kind of choice philosophy has been steadily increasing in the NHS over the last few decades (Greener, 2009). This can be interpreted as a form of neoliberal agency where people are expected to see themselves as assets to be nurtured and developed (Gershon, 2011). In the case of dying, patients are expected to manage their own death, including the details of where they would like to die, in order to have a good death. If neoliberalism seeks to realign the public and private and remake the subject (Kingfisher and Maskovsky, 2008), this can be observed in EOLC in the shift to promoting patient choice and discussions about death.

Through the practice of advance care planning as promoted in this EOLC policy, the locus of care is rooted in the individual patient, who is also responsible for participating in shaping what their death will look like. Others have argued that a focus on patient choice – as supported by these neoliberal discourses and practices – has the ability to shift the politics and relationality of care (Fine, 2007; Mol, 2008; Owens, 2015). It has been suggested that as the baby-boomers age, they are likely to demand a say in how they care cared for (Fontana and Reid Keene, 2009, p198). However, a growing body of research is critically exploring to extent to which people want to and are actively making decisions about their end of life care and what influences their preferences (e.g. British Social Attitudes Survey, 2012; Houben et al., 2014). Some research suggests that the most common dying trajectories that have no clear terminal phase may make it difficult for people to participate in advance care planning and that current policy does not reflect this norm (e.g. Barclay et al., 2011). Choice in EOLC represents an extension of the active citizenship now expected by

neoliberal governments in terms of healthcare (Bunton et al., 1995) and is reshaping

the way dying is experienced by changing discourses and shifting the responsibly of

care.

The growing rate of home deaths (Gomes et al., 2012) is largely supported by care

provided by family and friends (Payne et al., 2012). Whilst the choices often talked

about with the EOLCS focus around the individual, dying patient, there is a growing

interest in the needs and preferences of informal care-givers (e.g. Payne and Grande,

2013). For example, the recent review of choice in EOLC, whilst still primarily

outlining choice as an individual's preference, described how people's wishes may

reflect concerns they have for others and the relational-nature of the care-giving

environment （TCEOLCPB, 2015). This shift in policy is reflected in the research

literature that documents and promotes a relational way of envisioning care (such as

Carr et al., 2011).

Standardisation and Local Practices

End-of-life care policy fits a neoliberal model for policy design and implementation

through the emphasis on national standards being translated into local practice.

Standards are part of the neoliberal landscape as they are used to make claims to

credibility, maintain reputations and rationalise competition (Timmermans and

Epstein, 2010). The EOLCS can be viewed as producing a set of standards against

which the care of the dying should be managed and judged. This section describes

some of the tensions arising from this process, including the review and subsequent

withdrawal of the Liverpool Care Pathway (LCP).

The EOLCS recommended the use of specific tools in the care of the dying – such as the Liverpool Care Pathway (Ellershaw and Murphy, 2011) – and for thinking about EOLC more generally as a pathway of co-ordinated care over time. Even before the release of the EOLCS, 75% of hospices were using the LCP (DH, 2008b, p32); following the release of the EOLCS, hospitals were financially encouraged to use the tool (Neuberger et al., 2013). Many services across England, and even the globe, adopted the LCP as a way to demonstrate 'best practice' (Veerbeek et al., 2008). However, the LCP came under public scrutiny following several damning reports in public media about the use of the tool. Consequently, the use of the LCP was independently reviewed, with the recommendation that the tool was to be phased out of clinical practice (Neuberger et al., 2013). Instead of having a standardised pathway, as the LCP was viewed, it was recommended that patients have personalised care plans, even though researchers suggest current use of care plans may not meet the goals of the review (Burt et al., 2014).

Correspondingly, in 2014, advice for professionals providing EOLC was to produce local responses to the needs of the local population that fit within the local health and social care system (LACDP, 2014). This advice, however, presents an increased possibility of considerable variation in terms of how services are organised and how people are cared for, potentially re-enacting the 'postcode lottery' that was deemed one of the initial problems of previous care models. Although the NHS is a nationally funded system, the way care is delivered varies across localities and services thereby undermining the ability of standards to be universally met in the same way. Localism has received a mixed review as to whether it is the best mode of delivery for health care (Pratchett, 2004), and inequality in EOLC remains a topical issue (Dixon et al.,

2015). This response, however, fits with the NHS reform that has taken place under the Coalition government, which saw the creation of clinical consortia based on smaller geographical areas and motivated by business models (Ham, 2014). Promoting standardisation across these services, whilst accepting variability in translation of those standards, reflects the relationship of a neoliberal welfare government with the institutions through which political priorities are mobilised.

Future Directions

Continued press about EOLC – both in the form of scandals and in the promotional material supported by the Dying Matters Coalition – suggests that experiences of care towards the end of life are a societal issue and that more could be done to improve these experiences. The potential for EOLC to be a public health matter is increasing (Cohen and Deliens, 2012), with the development of compassionate cities, where communities support each other with dying and loss as part of everyday life (Kellehear, 2012). These initiatives are extending the principle behind advance care planning – talking about dying before death – beyond the medical sphere.

The EOLCS is being refreshed 'to align it with current needs of the population and changing health and social care landscape' (NHS England, 2014a, p5). Whilst it is commended for making huge improvements, it has 'highlighted' inadequacies within service delivery (Wee, 2014, p4). Although individual choice continues to feature heavily in policy rhetoric (e.g. TCEOLCPB, 2015), it is likely that future policy directives will acknowledge the structural elements that affect care outcomes. Lastly, the issue of funding palliative and end of life care remains unresolved, particularly

crossing the divide between social and health care services (NHS England, 2014b), as discussed in chapter 2.

Conclusion

End-of-life care policy in England has sought to change the way the care of the dying is organised and to increase public and professional conversations about dying. EOLC seeks to manage the dying process through advance care planning and patient choice. It is discursively supported by the universality of death and the increasingly predictability of dying. The EOLCS frames (some) previous practices and (lack of) political support as negatively affecting the way people die, suggesting that this is a social problem. Whilst some researchers and healthcare professionals have challenged elements of the strategy, and tools supported by the strategy have been abandoned (such as the Liverpool Care Pathway), the continued use of the term and amount of academic, professional, and public interest suggests that the field of end-of-life care will remain topical for some time. It is important, however, to realise the ways in which policy discourses are framing the issues, and the consequences this has for viewing dying and death as something that can be managed within a medical system.

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[i] The strategy is directed at England and Wales; a similar strategy was released in Scotland (Scottish Government, 2008) and in Northern Ireland (DHSSPSNI, 2010). Other countries have also created policy around end of life care (Macaden, 2011; The DH, 2010). The EOLCS can be accessed at: https://www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life (Last accessed April 22, 2015).

[ii] The NEOLCP was established in 2004 to promote 'best practice' in end-of-life care. In 2013 it was closed, with sections of its workload being merged into NHS Improving Quality.

[iii] A full list of the members can be access at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136440/EOLC_advisory_board_membership.pdf (Last accessed on February 15, 2015).

[iv] The NCPC is the umbrella charity for organisations involved in palliative, end of life, and hospice care in England, Wales, and Northern Ireland. See: http://www.ncpc.org.uk/ (Last accessed on February 15, 2015).

[v] The NEOLCP published monthly newsletters including personal stories and case studies to share 'best practice' through health and social care.

[vi] The evidence base for EOLC has been critiqued (Higginson, 1999).

[vii] End of life is typically referred to as the last year of life, although this can be difficult to prognosticate (e.g. Haga et al., 2012 for a comparison of methods) .

[viii] The concept of good death is problematic (Walters, 2004).

[ix] This organisation is currently part of Public Health England.

[x] This training is for workers in health and social care settings and is a direct result of the EOLCS. See: http://www.skillsforcare.org.uk/Skills/End-of-life-care/Working-together-to-improve-end-of-life-care.aspx (Last accessed on April 19, 2015).

[xi] E-ELCA is an e-learning project commissioned by the DH to support the EOLCS. See: http://www.e-lfh.org.uk/programmes/end-of-life-care/ (Last accessed on April 19, 2015).

[xii] Dying Matters seeks to change public attitudes and knowledge about death, dying and bereavement by encouraging more open communication. See: http://dyingmatters.org/

[xiii] Figures can be accessed from the NEOLCIN. See: http://www.endoflifecare-intelligence.org.uk/data_sources/place_of_death. (Last accessed April 21, 2015).

[xiv] These events were held at political party conferences by Marie Curie Cancer Care, Help the Hospices, and Sue Ryder. Whilst the EOLCS demonstrates some political commitment to EOLC, these events suggest that additional work was needed to keep EOLC high on the political agenda. The language of a demographic time bomb pre-dates the EOLCS (e.g. National Economic Development Office/Training Agency, 1989). Some researchers challenge the notion that an ageing population poses such challenges to the health service (Mullan, 2002; Spijker and MacInnes, 2013).

[xv] See Kaufman's work on death in American hospitals for an account of what these kinds of deaths may look like (Kaufman, 2005).