



Unexpected death in ill old age: An analysis of disadvantaged dying in the English old population



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ABSTRACT

The literature on death expectation in ill old age is mostly medical. A social science standpoint (especially quantitative) is practically absent. However, whether families, social and healthcare services can anticipate, support and prepare for the deaths of ill old adults is not reducible to the biomedical paradigm. Yet it is critical for end of life care (EOLC) policy. This study's aim is to investigate relatives' perception of death as unexpected in relation to both disease-related and care-related factors. Using the English Longitudinal Study of Ageing End-of-life Interviews Wave 6 this paper draws on probit regression analysis of unexpected (vs. expected) death in ill adults aged 50+. Findings are interpreted considering the containment of sudden death and the trajectories of dying in ill old age. The latter display overall visible decline preceding death. On this basis, EOLC literature and policy evidence death's uncertain timing as much as death's certain emergence in the horizon of expectation. Therefore, unexpected death in ill old age was interpreted as a failure to acknowledge dying, rather than the impossibility of discerning its approach. Very old age, dementia diagnoses and supported care environments were found to shape unexpected death.

1. Introduction

In the UK, the profile of death and dying has changed, and is continuing to change, as a result of the ageing of populations and the epidemiological transition to non-communicable diseases (DESA, 2012). In England, 69% of deaths are among the over-75s for whom chronic multi-morbidity, disability, dependency, and dwindling dying are more frequent (ONS, 2016a). However, unexpected death with continuing illness in old age has rarely been the object of study in both the medical and social sciences. Epidemiological insight into the trajectories of dying understands unexpected death as disease-free, disability-free and sudden (Lunney, 2003). This is not the case with most unexpected dying in old age. Furthermore, quantitative social science research into the social and care environment framing unexpected death in ill old age is nearly absent.

This is a knowledge gap in relation to the English End of Life Care (EOLC) policy's aim to anticipate, support and prepare for the dying of ill old adults in the community and within the social and health care systems. Given the uncertainty of timeframes for dying with organ failure, frailty, and dementia, whether these common forms of *dying in old age* are identified and supported early in the course of illness is a central concern of English EOLC policy and practice.

EOLC implies that dying is expected. Whether or not health care

practitioners (HCPs) recognise dying and provide adequate care, relatives play a unique and fundamental role in EOLC, which can be carried out only if death is expected (Grande et al., 2009). Therefore, this paper investigates whether *an expectation of dying* circulated among the relatives of chronically ill adults aged 50+. It does so by drawing on secondary analysis of unexpected (vs. expected) death reported in the English Longitudinal Study of Ageing (ELSA) End-of-life Interviews Wave 6. The bereaved relatives of deceased older adults are a difficult population to reach. The National Survey of Bereaved People in England is the only other large-scale survey of bereaved people. However, it does not report on death's expectation. Being the largest survey on old age at the English level, the ELSA End-of-Life Interviews dataset was a uniquely rich, reliable and under-explored source of data.

In the mid-1960s the British Hospice Movement pioneered the modern approach to holistic end-of-life care. To date, the UK is still regarded as setting international standards for the care of the dying (EIU, 2015). The 2008 English End of Life Care Strategy (EOLCS) was the first policy to address End of Life Care (EOLC) at the national level. The National Framework for Local Action 2015–2020 (NPEoLCP, 2017) renewed the Strategy's commitments by setting six goals for patient- and family-centred care and embracing the focus on choice introduced by recent policy reviews (DoH, 2016; Henry, 2015). However, there is growing concern that oncological models of palliative care do not meet

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the needs of an increasingly older population dying with multi-morbidity and dementia (Ellis et al., 2016).

Given the worldwide increase in late old age dying (DESA, 2012), how the English policy and healthcare systems are responding to it (or not) is of international interest. This paper contributes to the ongoing debate on EOLC policy in England (see Borgstrom and Walter, 2015) by discussing how late old age, institutional care and dementia diagnoses shape whether or not death is expected by relatives or others close to the deceased. Whether they know that death is approaching has consequences for how policy conceptualises EOLC, choice and (chosen or bio) family involvement.

The first section of the paper outlines cultural and policy expectations about dying in the UK. It also spells out the rationale for this study. The second section defines the study's design, scope, limitations and statistical methods. The third section reports all the study's results. The fourth section evidences the study's key findings considering the wider scenario of dying in old age and the care thereof. The fifth section discusses the findings' implications for English EOLC provision and policy.

2. Background

2.1. English End of Life Care policy and practice

In the UK, palliative and EOLC imply a specific vision of 'the good death'. The emphasis on *how* a life ends, that is a good dying rather than a good afterlife, is a modern Western invention. It developed with the secularisation, medicalisation and professionalisation of dying from the 18th century (Kellehear, 2007). In the Global North, the ideal of a good death prescribes a "healthy" or "safer" dying (almost) free from pain, dependency and helplessness (Kastenbaum, 1988). It coincides with the expectation of dying 'when the appropriate time comes', that is in old age, surrounded by our loved ones, that is typically 'at home', and continuing to be 'the same person', that is retaining mental capacity and control (Kastenbaum, 2009). Assisted suicide and euthanasia debates do not shift this ideal (and ideological) landscape (see Yuill, 2013). Hence, the modern vision of good dying demands preparation and a structure to be in place to reduce suffering and sustain the meaningfulness of a *life* by continuing relationships. A precondition for this is a shared, timely, and positive *expectation of dying* among the lay - not only the professional - entourage close to the dying person.

However, analysis of British EOLC policies reveals how difficult it is to translate these ideals into practice. The 2008 EOLCS set the benchmark for all EOLC policies across the UK (HSC Northern Ireland, 2016; Scottish Government, 2008; Welsh Government, 2017). The policies are similar in nature and assert needs-based access to care independently of diagnosis, age, and care setting. They also stress relatives' involvement in EOL decision-making and care. This is based on the understanding that dying can be accompanied by the loss of mental capacity and it involves social expectations and rites of passage which only relatives or people close to the decedent can fulfil. Aspects of EOLC provided by relatives may include: whether to withdraw or intensify treatment, preparing to say goodbye, ensuring post-death and funeral arrangements are discussed, writing a will, seeing a priest if desired or attending to existential and biographical issues in some other way (Walter, 2017). The major policy differences appear between the English and the Scottish documents in relation to how *expectation of dying* should be handled.

The English EOLCS adopts a "care pathway" or "transition" approach to care which depends on identifying a terminal phase (Fig. 1, Fig. 2 top). To deal with uncertain prognosis times and unpredictable dying trajectories, the policy encourages EOLC conversations with patients and relatives to take place from as early a stage as possible (DoH, 2008; NPEoLCP, 2017). By contrast, the Scottish EOLC policy adopts a "trajectory" model of care (Fig. 2 bottom). This approach integrates curative treatments with palliation, thus not depending upon the

individuation of a timeframe for dying to initiate EOLC conversations and delivery (Scottish Government, 2008). Although both policies affirm the primacy of clinical need over prognosis time to access EOLC, we noted that the English care delivery model is geared towards identifying a dying phase, while the Scottish model seeks to overcome the necessity to identify it. Hence, the English model does not promote an *expectation of dying* when prognosis is uncertain. The Scottish model instead encourages the disclosure of poor and uncertain prognoses as entry points to EOLC.

Nonetheless, EOLC does not come without issues in the whole UK. Concerns have been raised about EOLC quality and equity of access across services and social groups. Under-provision of specialist palliative care has been observed for non-cancer diagnoses, adults aged 85+, adults with dementia in inpatient settings as well as black and minority ethnic people (Dixon et al., 2015; Moriarity et al., 2012; NCPC, 2015). Despite catering for almost a quarter of the dying, the Care Quality Commission evidenced that care home staff lack appropriate training and support from external healthcare agencies (CQC, 2016).

2.2. Dying in old age in England

To date, death expectation has mainly been studied through the lenses of: 1) the dying trajectories associated with three disease groups common in old age, 2) palliative medicine, and 3) clinical expertise. While the biomedical perspective on death expectation is well-established, the lay and social perspective has rarely surfaced, a famous exception being Glaser and Strauss (1968).

Drawing on Lunney (2003) and Lynn and Adamson (2003), Murray and Sheikh (2008) established three distinct trajectories of functional decline associated with cancer, organ failure, frailty and dementia. These three trajectories of dying constitute the evidence-base informing the English and Scottish EOLC policies as well as the international palliative care literature (Murray and McLoughlin, 2012; Sands et al., 2015). The trajectories are constructed by retrospectively tracing disability levels within one year prior to death. Dying from cancer is a relatively linear process with a clearly disabling and identifiable terminal phase covering a few months (Fig. 3). On the contrary, organ failure, frailty and dementia display fluctuating disability levels covering many months. Dying from organ failure is an "intermittent" process punctuated by acute events which might (or might not) result in death. Dying from frailty and dementia is a "lingering" or "dwindling" process stretching over a protracted period. In either case, an accurate timeframe for dying is extremely difficult to predict. As a result, death can appear to be sudden or unexpected.

Likewise, palliative medicine does not provide any definitive criteria for prognosing dying across disease groups (Kennedy et al., 2014). Thus, the dying of old adults with longstanding (multi-)morbidity cannot be identified solely based on disease diagnosis. Nevertheless, clinicians' experiential judgement can be sufficient when the issue is to recognise a likelihood of dying in the foreseeable future (Glare et al., 2015). Hence, prognostic uncertainty hinders clinicians in planning ahead, but its very presence means that death has entered the horizon of expectation. On this ground, UK guidelines for HCPs uphold *expectation of dying within a year* as the basis for initiating EOLC (GMC, 2010).

The reviewed epidemiological and medical approaches to death expectation focus on the body as unique source of knowledge, ignoring that dying happens also as a *social relationship* (Kellehear, 2008). According to this biomedical logic, death is considered expected or unexpected in relation to the duration and intensity of the disabling symptoms. However, lay perceptions of expected or unexpected dying are never the object of study. Therefore, whether an *expectation of dying* circulated (or not) in a given social or care environment has not been investigated.

Further, such epidemiological studies of old age's dying trajectories cannot distinguish whether - in the presence of advanced chronic illness

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