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

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A B S T R A C T

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

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).
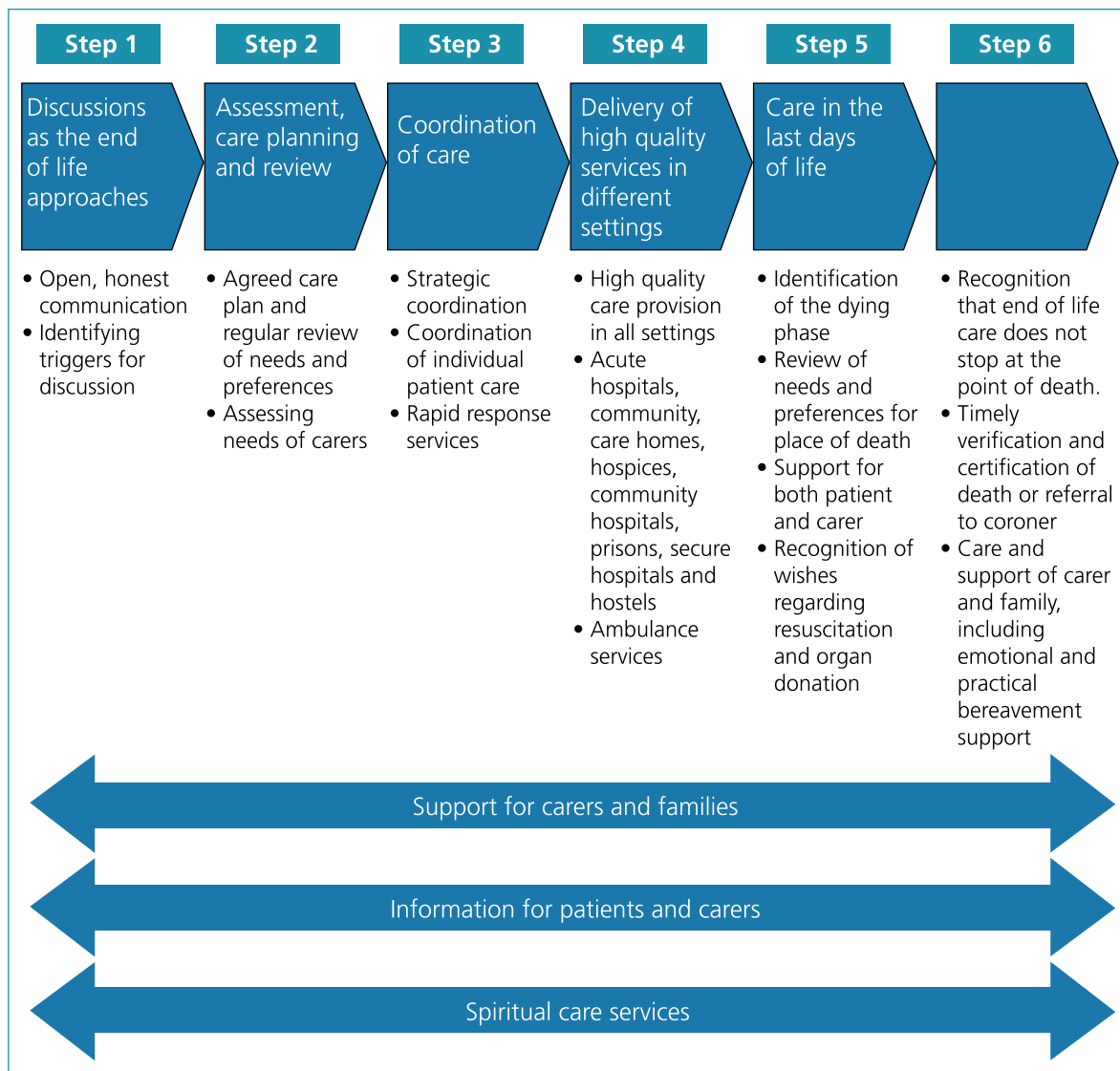
2.2. Dying in old age in England

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 beening investigated.

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

Step 1	Step 2	Step 3	Step 4	Step 5	Step 6
Discussions as the end of life approaches	Assessment, care planning and review	Coordination of care	Delivery of high quality services in different settings	Care in the last days of life	
• Open, honest communication • Identifying triggers for discussion	• Agreed care plan and regular review of needs and preferences • Assessing needs of carers	• Strategic coordination • Coordination of individual patient care • Rapid response services	• High quality care provision in all settings • Acute hospitals, community, care homes, hospices, community hospitals, prisons, secure hospitals and hostels • Ambulance services	• Identification of the dying phase • Review of needs and preferences for place of death • Support for both patient and carer • Recognition of wishes regarding resuscitation and organ donation	• Recognition that end of life care does not stop at the point of death. • Timely verification and certification of death or referral to coroner • Care and support of carer and family, including emotional and practical bereavement support

◄ Support for carers and families ►

◄ Information for patients and carers ►

◄ Spiritual care services ►

3.13 It is important to consider the support, care and information that is required by the person's family and caregivers both during the illness and into bereavement. Similarly, spiritual care and support for both the person and their carers is integral to the end of life care pathway.

3.14 When death follows a short acute illness steps 5 and 6 of the care pathway are relevant. Following a sudden death the pathway begins at step 6 (care after death).

Fig. 1. The EOLCS' end-of-life care pathway (DoH, 2008).

- a death was unexpected because it happened too suddenly and disability-free to be predictable or because of the failure to acknowledge and communicate an expectation of dying whose timing was uncertain.

This study targets precisely this question and, by doing so, it contributes to the social understanding of dying in ill old age which is relevant for EOLC policy and practice. It does so on three grounds: 1) the focus on relatives' perceptions of death in ill old age as unexpected (or expected), 2) the inclusion of both socially *and* medically oriented variables to predict perceptions, 3) the exclusion of disability-free

sudden deaths with longstanding illness.

3. Method

3.1. Design, scope and limitations

The study adopted a social science perspective on dying in ill old age by investigating those aspects which were excluded from the biomedical paradigm. The focus was on the lay views of the bereaved, not
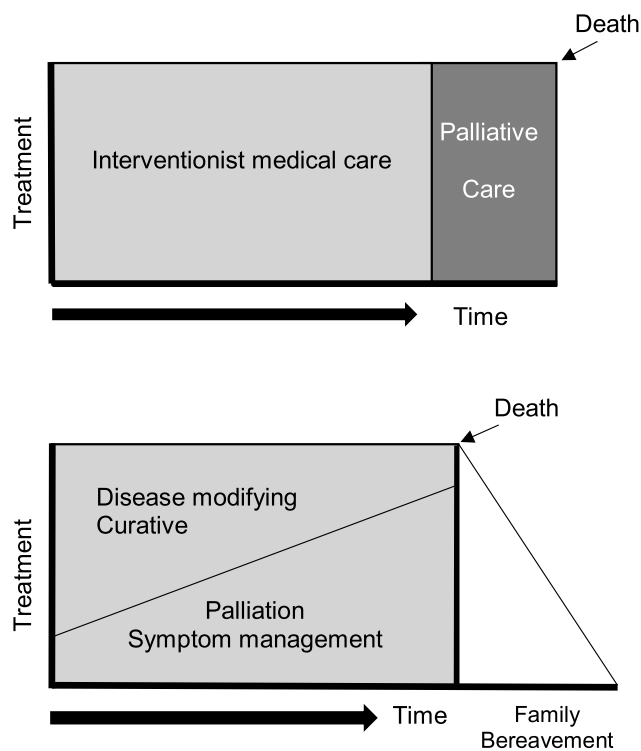
Fig. 2. The "transition" model of care versus the "trajectory" model of care (adapted from Lynn and Adamson, 2003).
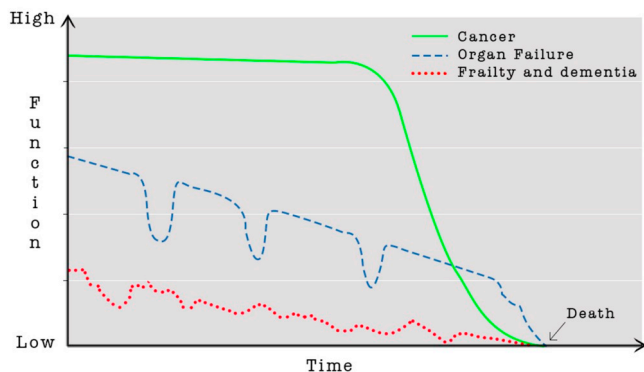

Fig. 3. The three typical end-of-life trajectories (adapted from Murray and McLoughlin, 2012, Fig. 3.1 cited Murray and Sheikh, 2008).

of social and healthcare professionals. 97.9% of proxy-respondents were relatives, partners, or cohabitees of the deceased. 2.1% were close friends. The study thus targeted how *expectation of dying* circulated within the dying's family and informal care network.

To reach this aim, the study included variables related to the social and care environment in which death occurred as well as the medical benchmarks of death in old age. The socially oriented variables, which did not feature in any epidemiological study of the dying trajectories, were: (1) place of death (hospital, home, hospice, care/nursing home), (2) time spent in place of death, (3) identity of the main carer (a relative, a friend, a home care professional, care/nursing home staff), (4) a living partner. The medically oriented variables were: (1) cause of death (cancer, respiratory, cardiovascular or other disease), (2) time spent being ill, (2) dying trajectory, (3) disability level (ADLs), and (4) eleven comorbidities including Alzheimer's and other dementias. The analysis included also sex and age of the deceased.

Probit regression analyses estimated the probability of each of the above variables to predict unexpected (vs. expected) death, holding all

other variables constant. This enabled simultaneous evaluation of the influence of the more socially as much as the more medically oriented factors on relative's perceptions of unexpected (vs. expected) death. In fact, many of the 'social' and 'medical' variables in the study are interrelated and influence each other. Therefore, to assess each of them holding all the others constant helped to isolate each variable's effect on the probabilities of unexpected (vs. expected) death.

Given the available data, there are some limitations as to what could be achieved. First, the survey retained only 240 proxy-respondents on a potential sample of 562 (NatCen, 2015). Second, the dataset did not allow to control for age, ethnicity and socio-economic background. Age could be retrieved from the Derived Variables datasets. Concerning ethnicity, the same process revealed that only four respondents out of 191 were non-white, the *Nonwhite* variable was thus dropped. Considering race inequalities in EOLC and the slim UK evidence-base about them (Dixon et al., 2015; Moriarity et al., 2014), it is problematic that so few nonwhite respondents were reached. No summary indicator for socio-economic background was available in the data.

These limitations are typical of analyses of large-scale survey datasets generated for multipurpose use rather than being collected by the researcher for a bespoke research question.

3.2. Data preparation

Missing data was replaced using the hot-deck imputation module developed for STATA by Mander and Clayton (2007) and the variables *Sex, Cause,* and *Place of death* as deck variables. Hot-deck imputation is a valid method for the substitution of small ($< 5\%$) as much as large (16–20% or more) proportions of data missing completely at random (MCAR) (Myers, 2011). The procedure preserves the salient features of the observed data, while retaining ease of implementation.

The original dataset comprised 240 cases. 9.6% of cases (N = 23) identified non-ill sudden deaths, these were removed along with causes of death recorded as 'Other'. This produced a final dataset of 191 deaths following illness. Missing data was almost 20%. However, Little's MCAR test was non-significant ($\chi^2 = 389.144$, DF = 381, p = .375), thus MCAR data was inferred.-The 38 missing data points were replaced using hot-deck imputation. These operations delivered a complete dataset of 191 cases.

The variable *Time in Place of Death* was not applicable to people dying at home (38 cases). A second dataset excluding home deaths was created. This dataset displayed 27.45% of missing data, but Little's MCAR test was non-significant ($\chi^2 = 356.355$, DF = 361, p = .559). Therefore, the 42 missing data points were replaced using hot-deck imputation. This delivered a complete dataset of 153 cases.

The original dataset reported the year of death, but not the *Age of the deceased*. The variable was obtained by manually recovering the year of birth from the Derived Variables datasets (wave 4, 3 and 2). Age was recoded as young-old (50–64 y/o), old-old (65–79 y/o), and oldest-old (80 + y/o). Dummy variables were created for each of the categories of the categorical variables (Tables 1 and 3 for the complete lists).

3.3. Statistical methods

To isolate the essential predictors of relatives not expecting the death, two restricted probit models were tested against two full probit models employing the log-likelihood (LR) test.

Unlike in linear probability models, probit regression coefficients are not good summary estimates of partial effects, rather Marginal Effects at the Means (MEMs) or Average Marginal Effects (AMEs) are better methods to estimate partial effects of each variable (Wooldridge, 2013). The MEMs are computed at the mean for every variable, x, representing the partial impact of a unit change in x when x is at its mean value and all of the other predictor variables are at their mean. The AMEs are the average of the marginal effects computed at every value

Table 1
First full probit model - AMEs.

	Dep. Var.: Unexpected Death	dy/dx	Std. Err.	z	Sig.	95% C.I. for Expt(B)	
						Lower	Upper
Cause of death	**Cancer**	**-.163**	.085	− 1.91	**.056**	-.331	.004
	Cardiovascular	.028	.083	0.34	.732	-.134	.191
	Respiratory	-.007	.104	− 0.07	.941	-.212	.197
	Other illnesses	Reference category					
Time ill	Time Ill 1d – 1w	.298	.244	1.22	.222	-.180	.777
	Time Ill 1w – 1m	.047	.142	0.33	.741	-.232	.327
	Time Ill 1m – 6m	.031	.081	0.39	.698	-.127	.190
	Time Ill 6m – 1y +	Reference category					
Place of death	Hospital	.131	.124	1.06	.289	-.111	.374
	Home	.073	.132	0.56	.578	-.185	.332
	Care/Nursing Home	-.025	.138	− 0.19	.857	-.296	.245
	Hospice	Reference category					
Dying trajectory	**Disability Free**	**.415**	.155	2.67	**.008**	.110	.719
	Rapid Decline	.101	.073	1.39	.166	-.042	.245
	Mixed Pattern	-.071	.117	− 0.61	.545	-.301	.159
	Gradual Decline	Reference category					
Disability	ADLs low	.157	.083	1.88	.060	-.006	.320
	ADLs medium	.095	.072	1.31	.190	-.047	.238
	ADLs high	Reference category					
Main Carer	Relative	.091	.080	1.13	.257	-.066	.249
	Friend	.147	.093	1.57	.116	-.036	.331
	Formal Home Care	-.050	.083	− 0.61	.542	-.214	.112
	Care/Nursing Home Staff	**.192**	.084	2.27	**.023**	.026	.359
Living Spouse/Partner		.115	.072	1.59	.112	-.026	.258
Comorbidities	Hypertension	.043	.061	0.71	.479	-.076	.162
	Heart attack	-.021	.102	− 0.21	.832	-.222	.179
	Congestive heart failure	-.110	.111	− 0.99	.321	-.327	.107
	Diabetes	-.048	.076	− 0.64	.524	-.199	.101
	Stroke	-.045	.076	− 0.60	.548	-.195	.103
	Chronic lung disease	.086	.080	1.08	.282	-.071	.244
	Cancer (comorbidity)	-.188	.109	− 1.73	.084	-.401	.025
	Parkinson's	.081	.159	0.51	.610	-.230	.393
	Psychiatric problems	.046	.105	0.44	.660	-.160	.252
	Alzheimer's	**-.478**	.125	− 3.82	**.000**	-.723	-.232
	Dementia	.142	.084	1.68	.093	-.023	.309
Age	Young-Old	Reference category					
	Old-Old	.084	.084	1.00	.317	-.081	.251
	Oldest-Old	**.246**	.071	3.46	**.001**	.106	.386
Sex		**.141**	.061	2.31	**.021**	.021	.262

Table 2
First restricted probit model - AMEs.

Dep. Var.: Unexpected Death	dy/dx	Std. Err.	z	Sig.	95% C.I. for Expt(B)	
					Lower	Upper
Cancer	**-.169**	.062	− 2.74	**.006**	-.291	.048
Disability Free	**.515**	.111	4.64	**.000**	.297	.733
Alzheimer's	**-.460**	.132	− 3.48	**.001**	-.719	-.201
Oldest-Old	**.185**	.057	3.25	**.001**	.073	.297
Sex	**.126**	.058	2.14	**.032**	.010	.242

of x, holding all other Xs constant. Averaging individual partial effects across the sample is better than providing partial effects for the sample average (Wooldridge, 2013), therefore, only AMEs are reported and evaluated in this study.

The 191 observations dataset fitted the first full probit model, and AMEs were computed for (Table 1). Restricted models were fitted retaining only the predictor variables that were significant in the full model until all coefficients were significant and did not cause any substantial reduction in log-likelihoods compared to the full model. The second attempt delivered the final restricted model and AMEs were computed for it (Table 2):

$P\ (y = 1|\mathbf{x}) = \Phi\ (\beta_0\ +\ \beta_1\text{Cancer}\ +\ \beta_2\text{DisFree}\ +\ \beta_3\text{Alzheimer's}\ +\ \beta_4\text{Oldest-Old}\ +\ \beta_5\text{Sex})$

The 153 observations dataset was analysed following the same procedure. AMEs were computed for the second full probit model (Table 3) and for the second restricted probit model (Table 4):

$P\ (y = 1|\mathbf{x}) = \Phi\ (\gamma_0\ +\ \gamma_1\text{Hospital}\ +\ \gamma_2\text{TimeInPlace1w1m}+\ \gamma_3\text{ADLsLow}+\ \gamma_4\text{CareHomeStaff}\ +\ \gamma_5\text{Alzheimer's}+\ \gamma_6\text{Dementia}\ +\ \gamma_7\text{Oldest-Old})$

4. Results

4.1. First restricted probit model

The first restricted probit model confirmed the variables Cancer, Disability Free, Alzheimer's, Oldest-Old and Sex as the essential predictors of unexpected (vs. expected) death for deaths in all places (Table 2).

The nested model showed less predictive power than the full model [Log-likelihood = −99.560, Pseudo R^2 = 0.191]. The reduction was not statistically significant compared to the full model [LR test $\chi^2(28) = 39.81$, $p > \chi^2 = 0.068$]. The overall absolute fit remained good [Pearson χ^2 test = 8.05, $p > \chi^2 = 0.886$; Hosmer-Lemeshow test: $\chi^2(7) = 3.83$, $p > \chi^2 = 0.799$]. The restricted model retained an overall high rate of correctly predicted outcomes (73.82% against 80.10% in the full model), but lost accuracy about unexpected death (39.39% against 60.61%).

As we might expect, the AMEs for the restricted model did not show

Table 3
Second full probit model - AMEs.

	Dep. Var.: Unexpected Death	dy/dx	Std. Err.	z	Sig.	95% C.I. for Expt(B)	
						Lower	Upper
Cause of death	Cancer	-.133	.092	− 1.44	.149	-.314	.047
	Cardiovascular	.048	.084	0.58	.564	-.116	.213
	Respiratory	-.089	.112	− 0.80	.426	-.310	.131
	Other illnesses	Reference category					
Time ill	Time Ill 1d – 1w	.468	.259	1.80	.071	-.040	.977
	Time Ill 1w – 1m	.080	.190	− 0.42	.673	-.454	.293
	Time Ill 1m – 6m	.047	.097	0.49	.626	-.144	.239
	Time Ill 6m – 1y +	Reference category					
Place of death	**Hospital**	**.332**	.143	2.31	**.021**	.050	.615
	Care/Nursing Home	.253	.167	1.51	.132	-.076	.582
	Hospice	Reference category					
Time in place	Time in Place 1d – 1w	.004	.153	0.03	.977	-.296	.305
	Time in Place 1w – 1m	**.318**	.121	− 0.19	**.009**	-.296	.245
	Time in Place 1m – 6m	.028	.123	0.23	.818	-.213	.270
	Time in Place 6m – 1y +	Reference category					
Dying trajectory	**Disability Free**	**Predicts success perfectly**					
	Rapid Decline	-.033	.086	− 0.38	.703	-.202	.136
	Mixed Pattern	.010	.131	0.08	.936	-.247	.268
	Gradual Decline	Reference category					
Disability	**ADLs low**	**.258**	.101	2.55	**.011**	-.006	.320
	ADLs medium	.128	.081	1.57	.117	-.031	.288
	ADLs high	Reference category					
Main Carer	Relative	.188	.100	1.88	.060	-.008	.384
	Friend	.158	.102	1.54	.123	-.042	.359
	Formal Home Care	.108	.109	0.99	.322	-.105	.322
	Care/Nursing Home Staff	**.207**	.085	2.43	**.015**	.039	.375
Living Spouse/Partner		.157	.083	1.89	.059	-.006	.321
Comorbidities	Hypertension	-.043	.069	− 0.62	.536	-.179	.093
	Heart attack	-.025	.138	− 0.18	.855	-.297	.246
	Congestive heart failure	-.122	.142	− 0.86	.391	-.401	.156
	Diabetes	.056	.087	0.65	.517	-.114	.227
	Stroke	.061	.078	0.79	.432	-.091	.214
	Chronic lung disease	.082	.093	0.88	.381	-.101	.266
	Cancer (comorbidity)	**-.276**	.132	− 2.10	**.036**	-.535	-.017
	Parkinson's	.103	.159	0.65	.517	-.209	.415
	Psychiatric problems	-.133	.132	− 1.00	.316	-.393	.126
	Alzheimer's	**-.543**	.114	− 3.76	**.000**	-.827	-.260
	Dementia	**.217**	.089	2.41	**.016**	.040	.393
Age	Young-Old	Reference category					
	Old-Old	.171	.105	1.62	.106	-.036	.378
	Oldest-Old	**.245**	.092	2.64	**.008**	.063	.427
Sex		.116	.068	1.69	.091	-.018	.251

Table 4
Second restricted probit model - AMEs.

Dep. Var.: Unexpected Death	dy/dx	Std. Err.	z	Sig.	95% C.I. for Expt(B)	
					Lower	Upper
Hospital	**.277**	.077	3.56	**.000**	.124	.430
Time in Place 1w – 1m	**.257**	.068	3.77	**.000**	-.123	.391
Disability Free	**Predicts success perfectly**					
ADLs low	**.174**	.072	2.39	**.017**	.031	.317
Care/Nursing Home Staff	**.206**	.088	2.34	**.019**	.033	.380
Alzheimer's	**-.595**	.163	− 3.64	**.000**	-.915	-.274
Dementia	**.293**	.087	3.34	**.001**	.121	.465
Oldest-Old	**.152**	.063	2.40	**.016**	.028	.276

dramatic changes in size with respect to the unrestricted model (compare Tables 2 and 1). What distinguishes the restricted model from the unrestricted one is that the partial effects of every variable are relative to all other values for that variable, not only to the reference category.

Considering Table 2, old adults dying from cancer (rather than any other condition) were 16.9 percentage points more likely to be expected by relatives to die. Old adults dying without disability and suddenly (rather than with some disability and non-suddenly) were 51.5 ppts more likely to be unexpected to die. Old adults with a diagnosis of

Alzheimer's (rather than without it) were 46 ppts more likely to be expected to die. Adults aged 80 + were 18.5 ppts more likely to be unexpected to die than adults aged between 50 and 79 y/o. Old females were 12.6 ppts more likely to be unexpected to die than old males.

These estimates relate to deaths at home, in hospital, hospice, and care/nursing home with or without disability and sudden death.

4.2. Second restricted probit model

The second restricted probit model (which excludes people who died at home and dropped all cases of disability-free sudden death) confirmed the variables Hospital, Time in Place of Death 1 week-1 month, ADLs Low, Care/Nursing Home Staff, Alzheimer's, Dementia and Oldest-Old as the essential predictors of unexpected (vs. expected) death for deaths in hospital, hospice and care/nursing home (Table 4). Disability Free predicted unexpected death perfectly and was dropped.

The nested model displayed less predictive power than the full model [Log-likelihood = − 66.163; Pseudo R^2 = 0.250]. However, the reduction was not statistically significant [LR test $\chi^2(27)$ = 37.34, $p > \chi^2$ = 0.088]. The overall goodness-of-fit continued to be good [Pearson χ^2 test = 41.90, $p > \chi^2$ = 0.431; Hosmer-Lemeshow test: $\chi^2(8)$ = 6.07, $p > \chi^2$ = 0.639]. The restricted model retained an overall high rate of correctly predicted outcomes (75.18% against 85.82% in the full model), but lost accuracy about unexpected death

(48.89% against 75.56%).

Considering Table 4, old adults dying in hospital were 27.7 ppts more likely to be unexpected to die than old adults dying in hospice or care/nursing homes. Old adults spending between a week and a month in place of death were 25.7 ppts more likely to be unexpected to die than old adults remaining in their place of death for a very short time or many months. Old adults with low levels of disability were 17.4 ppts more likely to be unexpected to die than old adults with high levels of disability. Old adults mostly taken care of by care/nursing home staff (rather than a relative, a friend or a formal carer at home) were 20.6 ppts more likely to be unexpected to die. Old adults with a diagnosis of Alzheimer's were 59.5 ppts more likely to be expected to die than old adults without it. On the contrary, old adults diagnosed with a non-Alzheimer's disease type of dementia were 29.3 ppts more likely to be unexpected to die than old adults without it. Adults aged 80 + were 15.2 ppts more likely to be unexpected to die than adults aged between 50 and 79 y/o.

These estimates relate to deaths in hospital, hospice, and care/nursing home, with disabilities and without sudden death while ill.

5. Key findings

The results highlighted five key findings. For relatives, 1) to die from cancer predicted expected death, 2) age 80 + predicted unexpected death, 3) to be cared for by care/nursing home staff predicted unexpected death, 4) a diagnosis of dementia other than Alzheimer's disease (AD) predicted unexpected death, and 5) AD predicted expected death.

The finding for cancer assumes the inclusion of disability-free sudden deaths. Thus, some cancer deaths were perceived as expected by relatives even if they happened suddenly and without disabling effects on the deceased. Lay perceptions of cancer deaths as expected relate to an understanding of cancer dying as a relentless, linear process. As we have seen, this understanding is supported by the international literature on EOLC and the trajectories of dying.

On the contrary, the findings related to age 80 +, institutional care, and non-AD dementia evidence that death was perceived as unexpected even when it occurred non-suddenly, with disability and with long-standing life-threatening illness. The containment of sudden death while ill is a unique and central feature of this study. It supports the claim that relatives did or did not expect death for reasons other than the too rapid progression from baseline functioning to death.

The key findings suggest that one of these reasons is the propensity of lay people to consider only AD (but not other types of dementia) and cancer (even when death is sudden and disability-free) as inevitably fatal illnesses. The suggestion that family caregivers and HCPs alike are more likely to consider cancer (rather than other life-threatening chronic conditions) as terminal was also made by an American study of prognosis in palliative care (Olajide et al., 2007). Likewise, an Italian study found that care home staff did not consider advanced demented patients to be terminal, but the study did not posit any difference between AD and other dementias (Di Giulio et al., 2008).

Another factor influencing relatives' perceptions of age 80 +, non-AD dementia, and institutional care deaths as unexpected can be the under-provision of EOLC to the same groups. Although it is reasonable to believe that the deaths of EOLC recipients will not be considered unexpected by relatives – as policy recommends family involvement in EOLC – this was not controlled by the study and cannot be assumed. Equally, the study cannot disentangle whether death was unexpected because no EOLC was provided by relatives (or HCPs) or whether no EOLC was provided by relatives (or HCPs) because death was unexpected. What can be assumed is the association between deaths relatives did not expect and relatives' failure to provide EOLC to the deceased. What can also be observed is the correspondence between patterns of unexpected dying as perceived by relatives and patterns of disadvantaged access to EOLC in England.

That age 80 + predicts that relatives' would not expect death reflects the under-representation of adults aged 85 + and non-cancer diagnoses in the English specialist palliative care services (SPCS). Excluding accidental deaths, the over-85s account for 39% of all deaths, but only 16.4% of them reaches SPCS (Dixon et al., 2015). Conversely, people below 65 y/o make up only 13.5% of non-accidental deaths, but they account for 23.8% of SPCS users (NCPC, 2014). One reason of the under-provision of palliative care to the oldest-old is that they are more likely than younger old adults not to be dying from cancer, while SPCS disproportionately cater for cancer diagnoses (NCPC, 2015).

That the presence of care home staff as main carers increased the likelihoods of relatives not expecting the death, mirrors Care Quality Commission and academics' claims that EOLC is not adequately provided within long-term care institutions for the aged (CQC, 2016; Smith, 2013).

That *dying in late old age* and *dying in care homes* in the UK are both forms of disadvantaged dying has been argued by previous qualitative research (see Gott et al., 2011; Harris, 1990). However, to date no quantitative study has shown that such disparities in the likelihood of death unexpected by relatives existed solely based on age 80 + and institutional care. The fact that family members were unaware of the approaching death of their chronically ill old relatives evidences that they did not provide any EOLC. This means that people close to the deceased could not prepare to say goodbye with them, plan and arrange for modality and place of care in the last days of life as well as provide emotional support sensitive to death-related issues, anxieties and pain.

In examining diagnoses of different types of dementia and whether a death was expected or not, the results were also illuminating. Alzheimer's disease (AD) predicted expected death and other types of dementia predicted unexpected death. AD predicted expected death for deaths in all settings; conversely, the effect of other dementia diagnoses emerged only for deaths in hospital, hospice and care/nursing home. This apparent asymmetry between AD and other dementias, and the extent to which death is expected or not as a result, has never been discussed in EOLC policy before. Moreover, dementia care literature does not differentiate between AD and other dementias when discussing implications for care management (Downs and Bowers, 2009). However, suggestions as to why AD predicts expected death and other dementias predict unexpected death can be found in the clinical features of AD and the other two most common types of dementia, that are dementia with Lewy bodies (DLB) and Vascular dementia (VaD).

AD presents a global, relentless accumulation of cognitively and physically disabling symptoms (Cantley, 2001). On the contrary, DLB displays fluctuating cognitive impairment and mild disorders of movement that can be "easily overlooked in an older person" (Cantley, 2001, p.16). Likewise, VaD manifests a focal and stepwise deterioration leading to language impairments, but sparing memory, reasoning or movement (Cantley, 2001). As a consequence, the relatively less disabling nature of DLB and VaD, combined with impaired communication, can hinder the recognition of these adults as dying. These aspects are likely to be exacerbated by emergency care settings preventing continuity of care (e.g. hospitals), not specialised in treating dementias (e.g. hospices), or already predictive of unexpected dying in our sample (i.e. care/nursing homes). In fact, when home deaths featured in the sample too, the effects of *other* dementias diagnoses were mitigated.

Nonetheless, research reports that *all* adults with *any type of dementia* are less likely to receive pain-control treatments and communicate their needs successfully (Sampson, 2006). Further research on the asymmetries between AD and other dementia diagnoses in relation to death's expectation is thus needed. On the other hand, the fact that deaths with AD are expected, but unlikely to receive adequate EOLC evidences that expectation of dying is a necessary, but not sufficient, condition for providing EOLC.

6. Implications for End of Life Care policy and practice

The findings evidence relatives' lack of awareness and involvement in the EOLC of adults aged 80 +, old adults living in care homes, and old adults with a non-AD dementia diagnosis. The lack of relative's involvement in EOLC is at odds with policy's aim to expand dying people's choice at the end-of-life. The first aim of the National Framework for Local Action 2015–2020 is to enable dying people, and their relatives, to have "honest, informed and timely conversations" about what matters to them and how to make it happen (NPEoLCP, 2017, p. 11). The fact that families were unaware of their relatives' dying means that such conversations never had the opportunity to take place, most likely to the detriment of dying people's wellbeing, agency and possibility to choose. Whether this was due to miscommunication (or neglect) between HCPs and families, or between families and dying people, was besides the scope of this study. Nonetheless, old peoples' care choices at the end-of-life have been shown to involve more complex issues and negotiations within families than the simple implementation of dying peoples' wishes through their relatives' intervention (Borgstrom and Walter, 2015).

Besides policy discourse on choice, dying peoples' relatives are both providers and recipients of EOLC. Their involvement in conversations about uncertain prognosis, care arrangements, carers' support and treatment choices are part of EOLC provision to families as much as post-death bereavement care. Therefore, the deaths of ill old adults unexpected by their relatives imply a failure to guide, sustain and support families and family carers when they are most in need of it.

The problematic nature of relatives' perceptions of death as unexpected is grounded in medical and policy acknowledgement that the impossibility of pinpointing an exact time for dying does not prevent identifying whether (or not) death has entered the horizon of expectation. As already noted, the current English EOLC framework (Fig. 1, Fig. 2 top) hampers the identification and management of *dying in late old age* as it is attuned to the more predictable timing of *dying from cancer*, rather than dying from organ failure, frailty and dementias (Fig. 3). Instead, the Scottish trajectory model of EOLC (Fig. 2 bottom) has the potential to handle these more unpredictable dying trajectories since it does not tie EOLC to the individuation of a terminal phase.

Despite policy commitment to needs-rather than prognosis-based access to EOLC, a cancer diagnosis still favours access to EOLC within the English healthcare system (NCPC, 2015). This is to the detriment of very old adults who are more likely to die from organ failure, frailty and dementia, and whose presence is not properly registered and addressed by the English EOLC policy. Furthermore, the overlap between very old age, institutionalisation and dementia is significant in the English population, thus producing a particularly disadvantaged form of dying in ill old age.

53.6% of the over-85s live in care homes (Wilson and Davies, 2009), care homes provide location for 58% of deaths above 65 y/o *with* a mention of dementia (Khera-Butler, 2016), and the over-80s mainly die *from* a type of dementia (ONS, 2016b). In spite of this, the public and policy profile of dying in care homes and from dementia remains low. No specific national strategy addresses old age dying (with dementia) in care homes (Smith, 2013) and dying *from* dementia emerged only after the updating of national statistics criteria for cause of death (ONS, 2016b). Moreover, the care home sector is largely deprived of stable partnerships with national healthcare agencies, and the Care Quality Commission inspection standards are too narrowly focused on the short time preceding death to promote EOLC (Froggatt et al., 2011).

Hence, EOLC policy and practice need to respond to the evidence that *dying in late old age* is different from dying from cancer at a younger age, and that English families as much as the social and healthcare systems are ill-prepared to attend to it.

7. Conclusion

This article reports the circumstances in which people are likely to anticipate a close relative's death. The study isolated the predictors of unexpected (vs. expected) death for two groups of ill old adults. First, those who died with or without disability (suddenly or non-suddenly, but always chronically ill) at home, in hospital, hospice, or long-term care. Second, those who died with disability (and never suddenly) in hospital, hospice, or long-term care. The key findings for the first group were that (1) cancer as the cause of death and (2) age 80 + predicted expected and unexpected death respectively. Findings for the second group confirmed age 80 + predicted unexpected death and revealed that (3) care/nursing home staff and (4) non-AD dementias predicted unexpected death. Conversely, (5) AD predicted expected death in both groups.

Relatives not expecting death in an old age characterised by chronic illness, frailty or dementia has been interpreted as neglected dying since it is assumed that evident signs of decline were neither acknowledged nor acted upon.

The five key findings also reflect a palliative care system in England centred on cancer care and death prognosis that disadvantages non-cancer diagnoses, all adults aged 80 +, old adults in long-term care, and old adults with dementia vis-à-vis access to EOLC. Given old age death's uncertain timing, only a positive and shared *expectation of dying* can enable EOLC to take place at the end of a long life. This is also the founding stone of the English EOLC policy promoting patients choice and family involvement in EOLC.

However, policy recommendations do not seamlessly translate into (good) practice. Based on this study, we advocate a longer-time perspective on dying in old age, in institutional care and with dementia, suggesting that the Scottish trajectory model of EOLC delivery is instrumental in reaching this aim.

Data access statement

This paper employed the End-of-Life Interviews Wave 6 of the English Longitudinal Study of Ageing (ELSA). The dataset can be accessed through the UK Data Service at http://doi.org/10.5255/UKDA-SN-5050-15.

Acknowledgements

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