

End-of-life decisions in the UK involving medical practitioners

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This study estimates the frequency of different medical end-of-life decisions (ELDs) made in the United Kingdom (UK) in 2007–2008, comparing these with 2004. Postal survey was carried out with 8857 medical practitioners, of whom 3733 (42%) practitioners replied, with 2869 having attended a person who died in the previous year. The proportion of UK deaths involving (1) voluntary euthanasia (0.21%; CI: 0–0.52), (2) physician-assisted suicide (0.00%) and (3) ending of life without an explicit request from the patient (0.30%; CI: 0–0.60) is low. Better questions about ELDs showed both non-treatment decisions (21.8%; CI: 19.0–24.5) and double effect measures (17.1%; CI: 14.6–19.6) to be much less common than suggested in earlier estimates, rarely involving intent to end life or being judged to have shortened life by more than a day. Continuous deep sedation (16.5%; CI: 14.3–18.7) is relatively common in UK medical practice, particularly in hospitals, home care settings and with younger patients. Further findings about the distribution of ELDs across subgroups are also reported. Survey research in this area requires careful control over question wording if valid estimates and comparisons of the prevalence of ELDs are to be made. The high rate of sedation compared with other countries may be a cause for concern. *Palliative Medicine* (2009); 00: 1–7

Key words: continuous deep sedation; euthanasia; physician-assisted suicide; terminal care; withdrawing treatment; withholding treatment

Introduction

A series of influential studies of end-of-life decisions (ELDs) have used survey methods pioneered in the Netherlands.¹ These have involved 5-year follow-up surveys^{2–4} studies in Belgium,^{5,6} and a comparative survey of six European countries.⁷ These studies were based on samples of death certificates using the same question wording for key variables. In Australia,⁸ a translated version of the same questionnaire was used to ask doctors about the most recent death they attended, extrapolating from this to generalise to the population of deaths by adjusting responses by the number of deaths each doctor attended in a year. A survey of general practitioners (GPs) in New Zealand⁹ used the same method as the Australian study. This method was then used in a study of ELDs taken during 2004 by United Kingdom (UK) medical practitioners, reported in this journal.^{10,11}

The UK survey found an overall rate of ELDs that was similar to that in Australia (nearly two-thirds of all

deaths) and a somewhat higher rate than several other European countries, largely because of a higher rate of ‘non-treatment decisions’ (NTD) (withholding or withdrawing treatments). It found relatively low rates of euthanasia and a nil rate of assisted suicide, contrasting with the Netherlands, Belgium and Australia, where these actions are more common.¹⁰ UK doctors were particularly consultative and cautious about shortening life.¹¹

This paper reports a second survey of ELDs made in the UK in 2007–2008, updating the earlier findings and using re-worded versions of key questions, to determine what is counted as an ELD. This re-wording aims to adjust for the potential of the original Dutch wording to overestimate the prevalence of certain ELDs. An extra question on ‘continuous deep sedation’ has been added, using the same wording as in surveys done in other countries,^{4,6} so that for the first time, a comparative estimate of the prevalence of this ELD in the UK can be made that avoids the problem of variations in wording that have affected other attempts at international comparison.¹² In addition, the new survey asks more questions about patients’ characteristics than the earlier UK survey, enabling comparisons of subgroups, and sampling permits comparisons between medical specialties.

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Definitions of ELDs

The following definitions of ELDs have been used for this survey

- Withdrawal or withholding a treatment occurs where, for example, chemotherapy is discontinued or a decision is made not to set up intravenous fluids. For the purposes of this survey, this is called a non-treatment decision (NTD) where a respondent considers it probable or certain that this would hasten the end of life or where they report an explicit intention to hasten the end of life.
- Providing drugs or other treatment is termed a ‘double effect’ decision if the respondent reports probable or certain knowledge that this would hasten the end of life or where the respondent reports partly intending to end life by these means.
- Euthanasia (‘voluntary’) occurs where, following a request from a patient, a drug is administered with the explicit intention of ending life.
- Ending of life without an explicit request from the patient occurs where a drug is administered with the explicit intention of ending life, but without a request from the patient (earlier studies have called this ‘involuntary’ euthanasia¹).
- Physician-assisted suicide occurs where a doctor intentionally provides a patient with a drug that enables the patient to end his or her own life.
- Continuous deep sedation occurs where a patient is continuously and deeply sedated or kept in a coma before death, using a drug such as midazolam.

The way in which these definitions were operationalised in the question wording is described below.

Methods

New questionnaire wording

A new questionnaire was designed with the help of an advisory committee (see ‘Acknowledgements’ section). The survey asked for the age, gender and cause of death of the person on whom the respondent reported. The new wording for identifying ELDs is shown in Box 1.

Questions about treatments (Q1a–Q1c) occur *before* questions about expectations or intentions associated with these treatments (Q2a–Q5), thus avoiding the conflation of these things in the Dutch-inspired surveys. For example, the Dutch questionnaire begins inquiries about ELDs with

Q1. Did you or another physician carry out one or more of the following acts (or ensure that one of them was carried out), taking into account the proba-

Box 1 Questions about end-of-life decisions

Q1. Concerning this death, did you or a colleague
Q1a. withhold a treatment^a (or ensure that this was done)?

Q1b. withdraw a treatment^a (or ensure that this was done)?

Q1c. use any drug to alleviate pain and/or symptoms?

Q2a. In withholding a treatment, did you or your colleague consider it *probable or certain* that this action would hasten the end of the patient’s life?

Q2b. In withdrawing a treatment, did you or your colleague consider it *probable or certain* that this action would hasten the end of the patient’s life?

Q3. Concerning the drugs used to alleviate symptoms, (Question 1c), were these administered

Q3a. knowing this would probably or certainly hasten the end of life?

Q3b. partly intending to end life?

Q4a. In withholding a treatment, did you or your colleague have the *explicit intention* of hastening the end of life?

Q4b. In withdrawing a treatment, did you or your colleague have the *explicit intention* of hastening the end of life?

Q5. Was death caused by the use of a drug prescribed, supplied or administered by you or a colleague *with the explicit intention* of hastening the end of life (or of enabling the patient to end his or her own life?)

^aIn this study, ‘treatment’ includes cardio-pulmonary resuscitation (CPR), artificial feeding and/or hydration.

bility or certainty that this act would hasten the end of the patient’s life

Q1a. withholding a treatment?

Q1b. withdrawing a treatment?

Q1c. intensifying the alleviation of pain and/or symptoms by using a drug?

This combines a question about what the doctor thought might happen, with a question about what the doctor did, whereas the new wording (Box 1) separates these things. As in other surveys using this method, doctors indicating a ‘yes’ to questions Q2a to Q5 were then asked a series of questions which included the estimated impact of ELDs on length of life (‘In your estimation, how much was the patient’s life shortened by the last mentioned act or omission?’). A further question using exactly the same

wording used in Dutch survey⁴ inquiring about continuous deep sedation was also added: ‘Was the patient continuously and deeply sedated or kept in a coma before death?’ Following the practice of the Dutch surveys to ensure comparability, no questions were asked about whether the decision to provide sedation was accompanied by an intention or estimated possibility, that this would shorten life.

Sampling and return of questionnaires

Binley’s database (www.binleys.com) of UK medical practitioners was used to send questionnaires to 8857 working UK medical practitioners, comprising separate random samples of 2829 GPs, 443 neurologists, 836 specialists in care of the elderly, 462 specialists in palliative medicine and 4287 in other hospital specialties (excluding specialties such as public health where doctors do not normally treat people who die). Two follow-up reminders were sent between November 2007 and April 2008. The sensitive nature of the subject matter was addressed by ensuring (as in earlier surveys using this method) that respondents knew their replies could not be traced back to them. No identifying marks were placed on the questionnaire, and a card was returned by respondents separately to indicate that a response had been made and no further reminders should be sent.

Response rate and response bias

The overall response rate was 42.1%. Specialists in palliative medicine produced the highest response rate (67.3%), followed by specialists in care of the elderly (48.1%), neurologists (42.9%), other hospital specialties (40.1%) and GPs (39.3%).

An investigation of response bias is reported elsewhere.¹³ Comparisons of responding doctors with national medical workforce statistics and a survey of non-responders (as in Fischer, *et al.*¹⁴) were done. As in Fischer, non-responders were not significantly different from responders in their degree of support for euthanasia or physician-assisted suicide. Non-responders tended to be younger, to have inadequate time to complete the questionnaire, and to believe it was only relevant to reply if they normally attended to dying patients or were involved in terminal care.

The patients reported on by responders (adjusting for specialty) were more likely to have died from cancer and less likely to have died from cardiovascular disease, than in national mortality statistics. For the analyses reported in this paper, all data are weighted by both doctor’s specialty and cause of death to make these mirror national proportions, except where breakdowns by cause of death are reported (Tables 3 and 4) where medical specialty alone is weighted.

Analysis

The following procedure for categorising ELDs was applied (shown in Box 2).

All results in this paper apply to the population of deaths rather than doctors. Of the 3733 responding doctors, 2869 (2923 before weighting) had, in the previous 12 months, attended a patient who had died, so it is these deaths on which this paper reports. Extrapolation from doctors’ replies to the population of UK deaths adjusts for the fact that different doctors attended different numbers of deaths in the following way:

- 1) Respondents were asked to estimate the average number of deaths where they would be the treating or

Box 2 Categorisation of end-of-life decisions from questions shown in Box 1

- 1) *Assisted dying*: where Q5 was ‘yes’. This included the following three sub-categories:
 - A) *Euthanasia (voluntary)*: if the drug was given by someone other than the patient at the explicit request (written or otherwise) of the patient.
 - B) *Physician-assisted suicide*: if the patient had taken the drug themselves.
 - C) *Ending life without an explicit request from the patient*: if no explicit request had been made.
- 2) *Alleviation of symptoms with possible life-shortening effect (‘presumed double effect’)*: where either Q3a or Q3b was ‘yes’. This included the following two sub-categories:
 - A) *Partly intending to end life*: if Q3b was ‘yes’.
 - B) *Knowledge of probable or certain hastening of end of life*: if Q3a was ‘yes’ and Q3b was not ‘yes’.
- 3) *Non-treatment decision*: where at least one of the following questions was answered ‘yes’: Q2a, Q2b, Q4a and Q4b. This included the following two sub-categories:
 - A) *With explicit intention of hastening the end of life*: if either Q4a or Q4b was ‘yes’.
 - B) *Knowledge of probable or certain hastening of end of life*: if either Q2a or Q2b was ‘yes’ and neither Q4a nor Q4b was ‘yes’.

If more than one question was answered ‘yes’ (1) prevailed over (2) and (2) prevailed over (3).

attending doctors during the course of a week, a month or a year. From these replies, an annual rate for each doctor was calculated.

- 2) Each doctor was then asked about the most recent death in the last 12 months for which they acted as the treating or attending doctor (or say whether they had not attended a death in the previous year).
- 3) Percentages of deaths and corresponding confidence intervals were calculated by treating the procedure as equivalent to cluster sampling with clusters of different sizes.¹⁵ Here, though, a 'cluster' is understood to be the total number of deaths attended by a doctor in a year and the choice of the last death attended is treated as a random way of selecting a death from the doctor's 'cluster' of deaths.

Results

Table 1 gives the percentage of deaths involving the ELDs measured in the study, comparing 2007–2008 with 2004. It shows, firstly, that 14% of deaths in 2007–2008 involve no treatments either being given or withheld and then (item 2) that in just under a further half of all deaths a treatment was given or withheld with no estimated possibility that this would have hastened the end of life. Next (item 3), the table shows a marked reduction in total ELDs between the two time points (from about two-thirds to about two-fifths). Continuous deep sedation is excluded from this figure to maintain comparability with

the earlier survey, where it was not asked about. Euthanasia, physician-assisted suicide and the ending of life without an explicit patient request ('involuntary' euthanasia¹) are rare or non-existent at both time points (items under 3a). The most common types of ELD (double effect and NTDs) show a marked reduction (items 3b and 3c). Unlike the earlier survey, the new survey estimates the extent to which double effect decisions (item 3b) and NTDs (item 3c) contained an intent to end life, showing that a small proportion of each of these involve an intention to end life, the rest involving knowledge that the action will probably or certainly hasten the end of life.

Table 1 also shows the rate at which continuous deep sedation is given (item 4). The figure of 16.5% is high compared with those for other countries where the same question has been asked (in the Netherlands, for example, the question resulted in a figure of 8.2% in 2005⁴; in Belgium, a similar question resulted in a figure of 8.3% in 2001⁶).

Table 2 shows the extent to which life was thought to have been shortened by an ELD, calculated both as a percentage of all deaths and as a percentage of deaths that involved one of the ELDs included in 3a–3c in Table 1. Nearly, a third of these cases were estimated to have involved no shortening of life at all; estimates of life shortening by more than 1 week are rare, affecting 4.3% of all UK deaths. Note that this excludes continuous deep sedation to maintain comparability with other surveys.

Table 3 shows the distribution of ELDs by characteristics of patients and doctors. Double effect decisions are reported at a particularly low rate by palliative medicine specialists and for deaths occurring in care homes, but at a

Table 1 Frequency of end-of-life decisions in 2007–2008 and 2004; percentage of deaths and 95% CI

	UK (2004)	UK (2007–2008)
1. No treatments given or withheld	—	14.0 (12.0–16.1)
2. Treatments given or withheld with no possibility of hastening end of life	—	46.9 (43.8–50.0)
3. Total end-of-life decisions (excludes continuous deep sedation)	63.6 (57.2–70.0)	39.2 (35.9–42.4)
3a. Assisted dying		
Euthanasia (voluntary)	0.16 (0–0.36)	0.21 (0–0.52)
Physician-assisted suicide	0.00	0.00
Ending life without an explicit request from patient	0.33 (0–0.76)	0.30 (0–0.60)
3b. Alleviation of symptoms with estimated 'double effect'		
Partly intending to end life	—	2.0 (1.2–2.9)
Knowledge of probable or certain hastening of end of life	—	15.1 (12.7–17.5)
Total	32.8 (28.1–37.6)	17.1 (14.6–19.6)
3c. Withdrawing/withholding treatment (non-treatment decisions)		
With explicit intention of hastening end of life		4.9 (3.5–6.4)
Knowledge of probable or certain hastening of end of life		16.8 (14.3–19.4)
Total	30.3 (26.0–34.6)	21.8 (19.0–24.5)
4. Continuous deep sedation	—	16.5 (14.3–18.7)
Number of doctors	733	2,869
Annual deaths attended by these doctors = 100%)	22,588	72,071

Bold indicates 2007–2008 is significantly lower. Figures for 2004 taken from Seale,¹⁰ Table 2.

Table 2 Estimated shortening of life; percentages and 95% CI^a

In your estimation, how much was the patient's life shortened by the last mentioned act or omission?	Percentage of all deaths	Percentage of deaths with an ELD ^b
More than 6 months	0.05 (0–0.1)	0.1 (0–0.25)
1–6 months	0.93 (0.29–1.57)	2.5 (0.7–4.2)
1–4 weeks	3.3 (2.3–4.2)	8.6 (6.0–11.2)
1 day–1 week	10.7 (8.5–12.9)	28.1 (23.0–33.3)
Less than 24 h	11.4 (9.1–13.7)	30.0 (24.7–35.3)
Life was probably not shortened at all	11.7 (9.7–13.7)	30.8 (25.9–35.7)
No. of doctors	2820	960
Annual deaths attended by these doctors (=100%)	70,712	26,858

^a49 doctors could not estimate the effect of an ELD on length of life so are excluded from this table.

^bIncludes assisted dying, alleviation of symptoms with possible life-shortening effect, withdrawing and withholding treatment. Excludes continuous deep sedation.

high rate in deaths occurring at home. NTD are rare in deaths from cancer and in deaths reported by palliative medicine specialists and GPs, but are reported at a high

rate for deaths occurring in hospitals or by doctors working in 'other hospital' specialties. Continuous deep sedation is reported more commonly for deaths of people aged up to 60 years, less commonly for people aged 80 years or more at the time of death. It is uncommon in cardiovascular deaths, deaths in care homes and deaths reported by neurologists; more common in deaths occurring in hospitals and at home than in other places, and more common in deaths reported by doctors working in 'other hospital' specialties than most other doctors.

Discussion

The prevalence estimates for ELDs using this re-worded survey questionnaire reveal markedly lower rates of NTD and double effect decisions with an estimated potential to end life, than in 2004. This suggests that the wording of the 2004 questionnaire, produced originally for studies in the Netherlands^{1–4} and then used in a series of influential studies across Europe and elsewhere,^{5–9} has encouraged doctors to include under these headings some decisions

Table 3 End-of-life decisions by characteristics of patients and doctors (percentages of deaths and 95% CI)

Characteristic	Euthanasia (voluntary)	Ending life with no request	Double effect	Non-treatment decision (NTD)	Continuous deep sedation	No. of doctors	Annual deaths attended by these doctors (=100%)
Age of patient							
<60	0.05 (0–0.15)	0.25 (0–0.59)	15.9 (10.2–21.6)	18.9 (12.7–25.1)	<i>26.5 (19.3–33.7)</i>	475	14,178
60–79	0.39 (0–1.13)	0.28 (0–0.64)	18.8 (15.0–22.6)	22.0 (17.2–26.6)	19.3 (15.5–23.1)	1,194	28,785
80+	0.12 (0–0.29)	0.34 (0–1.0)	16.1 (11.9–20.3)	23.0 (18.9–27.1)	12.3 (9.0–15.6)	1,186	28,397
Gender of patient							
Male	0.10 (0–0.24)	0.43 (0–1.02)	18.2 (14.7–21.7)	21.2 (17.5–24.9)	21.3 (17.4–25.2)	1,422	35,029
Female	0.31 (0–0.92)	0.18 (0–0.38)	16.7 (12.9–20.5)	22.1 (18.0–26.3)	16.0 (12.7–19.3)	1,379	35,103
Cause of death ^a							
Cancer	0.76 (0–1.72)	0.06 (0–0.12)	22.5 (18.3–26.7)	11.0 (7.9–14.1)	21.7 (17.5–25.9)	1,323	28,814
Cardiovascular	0.00	0.47 (0–1.13)	15.3 (8.8–21.8)	27.6 (21.4–33.8)	11.5 (7.1–15.9)	519	13,387
Other	0.07 (0–0.17)	0.00	17.3 (13.2–21.5)	26.4 (21.1–31.7)	19.0 (14.6–23.5)	905	22,822
Selected conditions							
Dementia ^b	0.00	0.00	19.9 (10.0–29.8)	28.3 (16.9–39.7)	12.7 (3.4–22.0)	197	4,106
Motor neuron disease	0.00	0.00	17.5 (0–43.9)	15.6 (0–38.8)	29.2 (0–59.2)	33	758
Place of death							
Hospital	0.19 (0–0.6)	0.39 (0–0.81)	17.9 (14.8–21.1)	<i>25.7 (22.3–29.1)</i>	<i>19.9 (16.6–23.2)</i>	1,660	51,816
Hospice/PCU	0.00	0.07 (0–0.21)	10.1 (2.1–18.1)	13.9 (2.6–25.2)	10.6 (2.9–18.3)	154	7,080
Care home	0.00	0.00	10.7 (7.1–14.3)	10.1 (3.5–16.7)	7.8 (4.6–11.0)	343	4,326
Own home	0.77 (0–1.6)	0.07 (0–0.21)	<i>23.9 (17.9–29.9)</i>	10.9 (6.5–15.3)	<i>22.4 (17.0–27.8)</i>	653	7,344
Other	0.00	0.00	21.0 (0.8–41.2)	2.3 (0–5.6)	14.2 (2.3–26.1)	36	454
Specialty of doctor ^c							
General practitioner	0.38 (0–0.95)	0.07 (0–0.21)	17.8 (13.5–22.1)	7.9 (5.7–10.1)	14.4 (10.5–18.3)	797	8,547
Palliative medicine	0.00	0.00	1.7 (0–3.5)	7.9 (4.0–11.8)	14.9 (9.6–20.2)	198	27,435
Neurology	0.00	0.00	13.0 (4.0–22.0)	39.6 (18.9–60.3)	4.9 (1.1–8.7)	120	1,614
Care of elderly	0.00	1.07 (0–2.36)	18.5 (12.9–24.1)	18.2 (13.1–23.3)	9.8 (5.7–13.9)	373	16,942
Other hospital	0.22 (0–0.68)	0.16 (0–0.32)	18.8 (15.4–22.2)	<i>29.7 (26.0–33.4)</i>	<i>19.4 (16.4–22.4)</i>	1431	46,970

Bold indicates a particularly low rate compared with others in that comparison (i.e. non-overlapping confidence intervals). Italics indicate a particularly high rate compared with others in that comparison (i.e. non-overlapping confidence intervals).

^aCause of death is weighted by specialty only.

^bDementia a cause of death or co-present with other main cause.

^cSpecialty is weighted by cause of death only.

that could have had no effect on the hastening of death. This study also confirms the finding of the 2004 study¹⁰ by showing that the incidence of assisted dying (euthanasia with or without a concurrent request, and physician-assisted suicide) in the UK is very low indeed, and that no cases of physician-assisted suicide are found in the UK with this survey method.

Even where decisions are taken with the belief that they may hasten death, it appears that in nearly a third of cases they are not regarded by respondents as in fact having affected the length of life. The study also confirms the finding of the 2004 survey¹¹ in showing that shortening life by significant amounts of time is rare in UK medical practice.

A review of studies estimating the prevalence of continuous deep sedation¹² has noted that comparisons are difficult where different definitions are used in surveys. This study uses the same wording as in surveys with similar designs done in other countries.^{4,6} The results show that deaths in UK are particularly likely to involve continuous deep sedation. This may be a cause for concern if interpretations of this as 'slow euthanasia'¹⁶ are to be avoided. A better understanding of the context in which these decisions are taken is needed to assess this.

Although a much larger number of doctors responded to this survey than the previous survey in 2004, enabling comparisons of sub-groups, the response rate to this survey was similarly low (although not for palliative medicine specialists), so particular efforts were made to assess the potential for response bias. This concluded that being a younger doctor and not attending dying patients was likely to have caused non-response. There was no tendency for responders to have different views from non-responders about the desirability of euthanasia or physician-assisted dying. Although, in spite of the steps taken to guarantee anonymity, legal prohibitions may have led to a reluctance to report actions that involved the deliberate ending of life, this will not have affected the validity of the comparison of the survey results with that of the earlier survey, as similar prohibitions applied then. On the same logic, comparisons between subgroups are also unaffected by this.

The initial idea for this survey is derived from initiatives by researchers in the Netherlands, where a very different medical culture and legal framework exists. Modifications to the design of key questions have been helpful in removing some of the misleading assumptions contained in the original Dutch questionnaire, producing results that now more closely reflect the realities of UK end-of-life care.

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Ethical approval

Ethical approval for this study was granted by the South East Research Ethics Committee REC 07/H1102/94.

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