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National survey of end-of-life decisions made by UK medical practitioners

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Background: This study estimates the frequency of different end-of-life decisions (ELDs) in medical practice in the UK, compares these with other countries and assesses doctors' views on the adequacy of current UK law. **Method:** Postal survey of 857 UK medical practitioners using a questionnaire used in other countries. **Findings:** The proportion of UK deaths involving an ELD were: 1) voluntary euthanasia 0.16% (0–0.36), 2) physician-assisted suicide 0.00%, 3) ending of life without an explicit request from patient 0.33% (0–0.76), 4) alleviation of symptoms with possibly life shortening effect 32.8% (28.1–37.6), 5) non-treatment decisions 30.3% (26.0–34.6). ELDs 1 and 2 were significantly less frequent than in the Netherlands and Australia; ELD 2 was also less frequent than Switzerland. ELD 3 was less frequent than in Belgium and Australia. Comparison of UK and New Zealand general practitioners showed lower rates of ELDs 4 and 5 in the UK. ELD 5 was more common than in most other European countries. A few doctors attending deaths felt UK law had inhibited or interfered with their preferred management of patients (4.6% (3.1–6.1%) of doctors) or that a new law would have facilitated better management (2.6% (1.4–3.8%) of doctors). **Interpretation:** The lower relative rate of ELDs involving doctor-assisted dying in the UK, and the relatively high rate of non-treatment decisions, suggests a culture of medical decision making informed by a palliative care philosophy. *Palliative Medicine* 2006; **20:** 3–10

Key words: euthanasia; physician-assisted suicide; right to die; terminal care; withdrawing treatment; withholding treatment

Introduction

End-of-life decisions (ELDs) in medical practice have become increasingly complex in recent years, involving a sometimes difficult balance of legal, ethical, medical and psychosocial issues. ELDs, for the purposes of this paper, can include: euthanasia and physician-assisted suicide (administering or supplying drugs to end life at the request of a patient); measures intended to end life without an explicit request from the patient; withdrawing or withholding treatments that potentially prolong life (called a 'non-treatment decision' (NTD) in this paper); and the alleviation of pain or other symptoms with treatments that are considered possibly or certainly to hasten death.

A 1990 survey of a representative sample of 3696 UK deaths in which relatives were interviewed after the death reported that in 2.4% of deaths a request for euthanasia was made, but no information was reported on whether the request had led to a medical action.[1] A 1994 survey of 312 NHS doctors in a single area of the UK showed that 12% reported having ever complied with a request to take active steps to hasten a death.[2] No significant or adequately designed survey of UK medical practices has since been published, although selectively interpreted surveys of medical opinions continue to be influential in the mass media.[3] The proportion of deaths in which euthanasia and other ELDs are made is therefore unknown for the UK. In the light of continuing legislative and professional interest in the issue of legalization of euthanasia or physician-assisted suicide,[4] it is desirable to have current factual information about medical practices in this area.

The paucity of information for the UK contrasts with a number of other countries where such information is more readily available. In the Netherlands, where doctors may openly practise euthanasia, surveys have established the proportion of deaths where particular ELDs are made.[5] Using a translated version of the Dutch questionnaire, similar surveys have been done in Australia,[6] New Zealand,[7] Belgium[8] and a European 'six countries' survey,[9,10] all of which used postal questionnaires.

The present study aims to estimate the frequency of different ELDs in medical practice in the UK, to compare these data with ELDs in other countries and to assess doctors' views on the adequacy of current UK law.

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Methods

Questionnaire

The questionnaire used for the Australian and New Zealand studies, which had been translated from the original Dutch into English, was used (with minor modifications for the UK context). The originators of this questionnaire avoided using terms like 'euthanasia' because they considered interpretation of such terms to be far from unanimous. Expressions were chosen that related as closely as possible to medical practice, so that answers could then be translated into the categories of ELD of interest. Key questions asked of every death where an ELD was possible (i.e., not sudden, or occurring before a doctor was able to attend) are shown in Box 1.

If 'yes' was answered to (c), respondents were asked to say who administered the drug. Where one or more ELDs were reported, respondents were asked whether they or a colleague had discussed this with the patient and whether the act or omission had been made in response to an explicit request from the patient.

For results reporting on the proportion of *deaths* (Tables 2 and 3), the procedure for categorizing ELDs taken by the European 'six countries' study[9] and the Australian study[6] was followed (shown in Box 2).

For results reporting on the proportion of *doctors* (Table 4), results are reported according to responses to the original questions as shown in Box 1, following the method of the New Zealand study[7] where these comparisons are relevant.

Additionally, doctors who attended a death, excluding those whose first contact was after the death, were asked for their views about UK law using the questions shown in Box 3.

Box 1: Questions asked about ELDs

(a) Did you or a colleague withhold or withdraw treatment
- taking into account the probability or certainty that this action would hasten the end of the patient's life or
- with the explicit intention of not prolonging life or hastening the end of life?

(b) Did you or a colleague intensify the alleviation of pain and/or symptoms using morphine or a comparable drug
- taking into account the probability or certainty that this action would hasten the end of the patient's life or
- partly with the intention of hastening the end of life?

(c) 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?)

Box 2: Categorization of ELDs from questions shown in Box 1

(1) *Doctor-assisted dying:* where question (c) was answered yes. This included the following three sub-categories:
  (i) *Euthanasia (voluntary):* if the drug was given by someone other than the patient at the explicit request (written or otherwise) of the patient.
  (ii) *Physician-assisted suicide:* if the patient had taken the drug themselves
  (iii) *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:* where at least one of the questions in (b) was answered yes.

(3) *Non-treatment decision:* where at least one of the questions in (a) was answered yes.

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

Sample

A random sample of 1000 general practitioners (GPs) and 1000 hospital specialists listed on Binley's database (www.binleys.com) of all working UK medical

Box 3: Questions about the adequacy of UK law

(d) Did your perception of the law, as it applies in the UK, inhibit or interfere with your preferred management of the patient and end of life decision?

(e) (If yes to (d)) Would enactment of laws providing defined circumstances in which a drug may be prescribed and/or administered to patients with a terminal illness, with the explicit purpose of hastening the end of life, have enabled your patient to receive better and more appropriate care?

practitioners (updated in September 2004) were sent questionnaires, with two follow-up reminders, between October and December 2004. Following the method of the Dutch survey in which the questionnaire originated[11] and the Australian survey,[6] which replicated this aspect of the Dutch survey, specialties where doctors could not be expected to have attended a death in the previous year (eg, public health) were excluded (these are listed in Box 2 of Kuhse *et al*.[6]).

Ethical approval for this study was granted by the Thames Valley Multi-centre Research Ethics Committee (Ref: 04/MRE12/32).

Response rate and weighting

A variety of strategies have been recommended to increase response rates to postal questionnaires.[12] This survey used an attractively designed questionnaire with a reply-paid envelope, stressed the importance of the topic and the brevity of the questionnaire, and sent two follow-up reminders. The sensitive nature of the subject matter (known to be a factor that decreases response rates) was addressed by ensuring 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.

After three mailings, 857 usable questionnaires were returned. An additional 80 questionnaires were 'returned to sender' because the doctor had left the post (most of these being doctors in training grades), leaving 1063 non-responders. Telephone calls to the addresses of 100 doctors randomly selected from these 1063 established that 29 of these were not known at that address, 20 of these being doctors in training grades who had left their posts in the summer before the survey began. Extrapolating this percentage to the remaining non-responders gives a response rate of 53% (857/1612), close to the 54% mean response rate of physician postal surveys published in medical journals.[13] This method of reporting response rate follows the CASRO code of standards for survey research.[14] Other surveys using the questionnaire have achieved response rates of 48% for New Zealand,[7] 52% for Belgium,[8] 64% for Australia[6] and between 44% and 75% in the European 'six countries' study.[9,10]

Results reported in this paper are weighted to adjust for differences in the overall numbers of GPs and hospital specialists in the population of UK doctors (except where GPs and hospital specialists are reported separately). Additionally all results are weighted by each specific combination of doctor's age and sex to reflect proportions in the UK medical population in 2004 (derived from secondary analysis of data supplied by UK government statisticians responsible for annual medical workforce surveys), making the sample representative of UK doctors and eliminating the response bias otherwise produced by the under-representation of doctors in training grades.

Analysis

The Australian[6] and New Zealand[7] studies surveyed doctors, asking them to report on the most recent death attended; the others sampled death certificates and then approached attending doctors. With the exception of the New Zealand study, which reported only for GPs, these surveys allow estimates of the proportion of deaths receiving particular ELDs, either by being based on a random sample of death certificates[8–10] or by extrapolating this from the replies of a sample of doctors,[6] adjusting for the fact that different doctors report attending different numbers of deaths. The study reported here uses this last method which proceeds as follows:

1. Respondents were asked to estimate the average number of deaths where they would be the treating or attending doctors during the course of a week, a month or a year. From these replies an annual rate for each doctor was calculated. (Table 1 reports the annual numbers of deaths attended by the doctors.)
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. Following exactly the method of the Australian survey,[6] percentages of *deaths* and corresponding confidence intervals are calculated by treating the procedure as equivalent to cluster sampling with clusters of different sizes.[15] Thus deaths occur in clusters centred on their attending doctor, the requirement to select the most recent death being a method for random selection within the cluster. This method of calculation applies to UK and Australian data in Tables 2 and 3.

For results reporting on the proportion of *doctors*, percentages and confidence intervals were calculated using standard formulae applicable to simple random

Table 1 Annual number of deaths attended by doctors (GPs and selected hospital specialties)

	GPs	Hospital specialists	All*
Number of deaths in the last year	3884	17 253	22 588
Mean	9.1	39.9	26.4
SD	12.2	51.5	42.2
Number of respondents	424	433	857

*'All' is weighted to conform to proportions of GPs/these hospital specialists in the UK medical population.

Table 2 Frequency of ELDs in UK and Australia; percentage of deaths and 95% CI

	UK (2004)	Australia (1996)
Total ELDs	63.6 (57.2–76.4)	64.8 (61.9–67.9)
Euthanasia (voluntary)	**0.16 (0–0.36)**	1.8 (1.2–2.4)
Physician-assisted suicide	**0.00**	0.1 (0.02–0.18)
Ending life without an explicit request from patient	**0.33 (0–0.76)**	3.5 (2.7–4.3)
Alleviation of symptoms with possible life-shortening effect	32.8 (28.1–37.6)	30.9 (28.0–33.8)
Non-treatment decisions	30.3 (26.0–34.6)	28.6 (25.7–31.5)

Bold type indicates UK is significantly lower.
Figures for Australia taken from Kuhse *et al.*,[6] table 4.

sampling (as in Table 4 and in non-UK results in Table 3).

Results

Table 2 shows the rate of ELDs for all UK deaths that involve an attending or treating doctor, allowing a direct comparison with Australian deaths. It shows lower rates in the UK for (voluntary) euthanasia, physician-assisted suicide and ending of life without an explicit request from the patient.

Table 3 compares the UK study in 2004 with the European 'six countries' study,[9] excluding sudden and unexpected deaths. Sudden and unexpected deaths are excluded from Table 3 to control for an artefactual effect that applied to this and the Australian study, which chose deaths according to the most recent one nominated by the respondent. Significantly fewer such deaths were nominated by UK and Australian doctors than in studies based on samples of death certificates. The effect of this is to artificially inflate the proportion of deaths receiving ELDs, a point not appreciated by the Australian investigators. Table 3 shows that ELDs in the UK, and within this, NTDs, are more common than in Belgium, Denmark, Italy and Sweden. Doctor-assisted dying is less common than in Belgium or the Netherlands and its three subcategories show either no significant difference or lower rates than in other countries.

Table 4 allows direct comparison of UK GPs with New Zealand GPs. It shows that UK GPs report significantly lower rates of ELDs overall, and for all individual ELDs except supplying or administering a drug with the intention of causing death, where there is no significant difference.

Table 5 gives the results for doctors' views about the degree to which UK laws inhibited or interfered with their management of patients, showing that it is rare for UK doctors to feel UK law did this, with no significant difference between hospital specialists and GPs.

Respondents were asked at the end of the questionnaire to write comments clarifying or expanding on answers to previous questions. Most comments referred to the circumstances of the particular death. Fifty-one comments (unweighted) contained sentiments about the desirability of legal change or of medical involvement in hastening death. Of these, 42 (82%) expressed opinions indicating support for the current situation, consisting of statements opposing medical involvement in hastening death or to any change of the law. Seven (14%) showed dissatisfaction with present laws. The two remaining comments contained mixed views. A selection of these comments is shown in Box 4.

Discussion

The proportion of UK deaths involving all three forms of doctor-assisted dying (voluntary euthanasia, physician-assisted suicide and ending life without an explicit request from the patient) was extremely low. All categories of doctor-assisted dying were lower than in Australia. Voluntary euthanasia, physician-assisted suicide and ending life without an explicit request from a patient were either lower or not significantly different from six other European countries. For GPs other ELDs (non-treatment decisions and alleviation of symptoms with possible life-shortening effect) were lower in the UK than in New Zealand. No difference was found on these in comparison with the Australian study. NTDs were more common than in four out of six European countries. Doctors attending deaths rarely felt UK law to have inhibited or interfered with their preferred management of patients or for new laws in this area to be desirable.

Self-reporting may be affected by the sensitivity of the topic in surveys like this, although measures were taken on this study (as in studies in other countries) to anonymize responses and reassure respondents that their identities could not be traced. If this effect applied, it will have been to reduce estimates of intentional hastening of death by doctors. Caution should therefore be exercised in interpreting absolute rates of ELDs. Assuming, though, that similar factors affected the response in other countries where intentional hastening of death is illegal, comparisons across countries using the same methods can be considered valid.

Campaigners for liberalization of the laws covering the intentional hastening of patients' deaths like to point to studies of this sort that demonstrate high levels of ending life without an explicit request for the patient (for example, the Australian study[6] and an early study in Belgium[8]). This, so the argument goes, demonstrates the unregulated practice of euthanasia without consent in countries where criminalization breeds fear of bringing

Table 3 Frequency of ELDs for non-sudden deaths: European countries compared; percentage of deaths and 95% CI

	UK (2004)	Belgium (2001–2002)	Denmark (2001–2002)	Italy (2001–2002)	Netherlands (2001–2002)	Sweden (2001–2002)	Switzerland (2001–2002)
Number of non-sudden deaths	629 (extrapolated to 20 235)	1942	1963	1852	3574	2248	2282
No ELD	29.8 (23.1–36.5)	**41.0 (38.8–43.2)**	**38.9 (36.7–41.1)**	**67.5 (65.4–69.6)**	34.6 (33.1–36.2)	**49.1 (47.0–51.2)**	25.0 (23.2–26.8)
Total ELDs	70.2 (63.6–76.8)	*59.0 (56.8–61.2)*	*61.1 (58.9–63.3)*	*32.5 (30.4–34.6)*	65.4 (63.8–67.0)	*50.9 (48.8–53.0)*	75.0 (73.2–76.8)
Doctor-assisted dying	0.54 (0–1.16)	**2.78 (2.05–3.51)**	1.17 (0.7–1.64)	0.16 (0–0.34)	**5.12 (4.4–5.84)**	0.31 (0.08–0.54)	1.53 (1.03–2.03)
Euthanasia (voluntary)	0.17 (0–0.51)	0.46 (0.17–0.75)	0.10 (0–0.24)	0.05 (0–0.15)	**3.89 (3.49–4.29)**	–	0.39 (0.13–0.65)
Physician-assisted suicide	0.00	0.05 (0–0.15)	0.10 (0–0.24)	0.00	**0.31 (0.13–0.49)**	–	0.52 (0.22–0.82)
Ending life without an explicit request from patient	0.36 (0–0.87)	**2.26 (1.59–2.93)**	1.02 (0.57–1.47)	0.11 (0–0.26)	0.90 (0.59–1.21)	0.31 (0.08–0.54)	0.61 (0.29–0.93)
Alleviation of symptoms with possible life-shortening effect	36.3 (29.9–42.6)	33.4 (31.2–35.6)	38.9 (36.7–41.1)	*26.7 (24.7–28.7)*	30.1 (28.6–31.6)	30.3 (28.4–32.2)	32.3 (30.4–34.2)
Non-treatment decisions	33.4 (27.1–39.8)	*22.8 (20.9–24.7)*	*20.9 (19.4–22.4)*	*5.6 (4.6–6.6)*	30.1 (28.6–31.6)	*20.2 (18.5–21.9)*	41.1 (39.1–43.1)

Figures where the UK is significantly lower are marked in bold type; figures where the UK is significantly higher than that country are italicized and underscored. Figures for countries other than the UK calculated from van der Heide *et al.*,[9] table 2.

Table 4 Frequency of ELDs by UK and New Zealand GPs (numerator/denominator, percentages of doctors and 95% CI)[a]

	UK (2004) GPs	New Zealand (2000) GPs
(1) Probability that end of life hastened by:		
(a) Withholding a treatment	**41/415**	258/1255
	9.9 (7.0–12.8)	20.2 (16.9–23.5)
(b) Withdrawing a treatment	**32/412**	200/1255
	7.8 (3.0–10.4)	15.9 (13.9–17.9)
(c) Intensifying alleviation of pain or symptoms	**142/420**	588/1255
	33.8 (29.3–38.3)	46.9 (44.1–49.7)
(2) Intention of intensifying alleviation of pain or symptoms was partly to end life	**17/421**	172/1255
	4.0 (2.1–5.9)	13.7 (11.8–15.6)
(3) Action with explicit purpose of not prolonging life or hastening death:		
(a) Withholding a treatment	**15/417**	130/1255
	3.6 (1.8–5.4)	10.4 (8.7–12.1)
(b) Withdrawing a treatment	**11/413**	71/1255
	2.7 (1.1–4.3)	5.7 (4.4–7.0)
(4) Supplying or administering drug to cause death	6/422	39/1255
	1.4 (0.3–2.5)	3.1 (2.1–4.1)
Any ELD	**166/424**	693/1255
	39.2 (34.6–43.8)	55.2 (52.4–57.9)
Attended a death in past year	352/424	1100/1255
	83.0 (79.4–86.6)	87.6 (85.8–89.4)
Did not attend a death in past year	72/424	155/1255
	17.0 (13.4–20.6)	12.4 (10.6–14.2)
Total (=100%)	424*	1255

[a]Percentages and confidence intervals for the UK reflect small numbers of missing data for some variables. The denominator therefore varies from the total in some instances.
ELDs 1c and 2 are the individual questions that make up the category 'alleviation of symptoms with possible life shortening effect' in Tables 2 and 3.
ELDs 1a, 1b, 3a and 3b are the individual questions that make up the category 'non-treatment decisions' in Tables 2 and 3.
ELD 4 in this table includes voluntary euthanasia, physician-assisted suicide and ending of life without an explicit request from the patient, which were not reported separately for the New Zealand survey. In Table 3 these are called 'doctor-assisted dying'.
Bold type indicates UK GPs are significantly lower than New Zealand GPs.
Figures for New Zealand calculated from data reported in Mitchell and Owens.[7]

the issues out into the open. Because the rate of this ELD is relatively low in the UK, this argument cannot be made. On the other hand, the study shows that both voluntary and 'involuntary' euthanasia occur in a small number of deaths, so the practice is not unknown in the UK.

The lower relative rate of ELDs involving doctor-assisted dying in the UK, and the relatively high rate of NTDs, suggests a culture of medical decision making informed by a palliative care philosophy. Historically the UK developed palliative care approaches earlier than the other countries in which the survey has been done, supporting this interpretation. The situation may also reflect, amongst GPs in particular, fears arising from the Harold Shipman scandal in which a UK GP was convicted of causing the deaths of numerous patients by administering lethal injections. Most of the doctors in the survey appear happy with the state of UK law in this area, although a small proportion felt the existing law has interfered with their care for the patient on whose care they reported. Policy makers and legislators should be aware of this situation in any new considerations concerning a change of law.[4]

A study based on interviews with attending doctors could gather fuller information about the context in which particular decisions are made. Respondents' qualitative comments suggest that ELDs are rarely simple matters and fuller investigation of the particular circumstances of individual deaths is likely to provide a deeper appreciation of medical practices in this area.

Table 5 Views of UK doctors attending deaths about the application of UK law: percentages saying 'yes' to questions (d) and (e) in Box 3 (percentages and 95% CI)

	GPs	Hospital specialists	All[a]
Question (i) (law interfered)	5.1 (2.8–7.4)	4.2 (2.2–6.2)	4.6 (3.1–6.1)
Question (ii) (new law would have helped this patient)	2.8 (1.1–4.5)	2.4 (0.9–3.9)	2.6 (1.4–3.8)
Total (=100%)	352	378	733

[a]'All' is weighted to conform to proportions of GPs/hospital specialists in the UK population.

Box 4: Selected comments of doctors about ELDs and UK law

A. In favour of the current situation

(1) Comments against medical involvement in hastening death

I could not actively assist a suicide as it is against my religious belief.

I would be very concerned if doctors 'helped' patients to end the patient's life. Everyone has to die. The process of dying is often very unpleasant but I feel that doctors will cheapen life, destroy our trust/relationship with our patients . . . I feel that if doctors cross the line, of helping patients to die we will destroy so much that is important in the profession.

With regards to explicitly hastening death I do not believe this is the correct course of action. Decent palliative care is about improving the life remaining to patients.

(2) Comments against a change in the law

I do not feel that there needs to be a change in the law – we already have powers to prescribe to allow alleviation of suffering. I don't think our role is to *actively* end life/quicken death explicitly.

I would feel very wary of the introduction of new legislation to facilitate euthanasia; this doesn't mean I would oppose it; simply that I would not welcome inappropriate interference with the current laws.

Introducing laws into this area would be a clumsy and blunt tool and is likely to make care worse.

It would be a *disaster* if physician assisted suicide were legalised.

I hold Christian fundamentalist views and would oppose any decision in these circumstances where the primary aim is to shorten life.

B. Comments showing dissatisfaction with present laws

In certain cases, hastening death is more appropriate but law doesn't allow.

I am increasingly worried about medico-legal risks in medicine. It is easier to let someone suffer and die than make a conscious decision to withdraw treatment to shorten life.

I understand that I am not always acting in strict accordance with the law. I am performing my duties to my patients to the very best of my abilities. I feel that the tighter the law becomes the more difficult it becomes to do this job caringly and compassionately.

C. Mixed views

It is getting more difficult to treat patients appropriately. I am strongly against euthanasia, but increasingly feel compelled to strive officiously and inappropriately to keep alive.

I personally would like to have euthanasia available to end my own life if appropriate.

I would not wish to participate in euthanasia for any of my patients – it is too complicated.

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