

Characteristics of end-of-life decisions: survey of UK medical practitioners

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Background: To assess the extent to which UK doctors discuss end-of-life decisions (ELDs) with patients, relatives and colleagues, and to assess the degree to which patients' lives are shortened by ELDs. **Method:** Postal survey of 857 UK medical practitioners. Comparison of UK data with published data from other countries, permissive and not permissive of medical involvement in actively hastening death. **Findings:** UK doctors, compared with those in permissive and non-permissive countries, are relatively cautious in shortening life by more than a few days. Willingness to discuss ELDs with patients and relatives is relatively high in the UK, but not as high as in permissive countries. UK doctors are highly likely to discuss ELDs with colleagues, and are more likely to do this than doctors in other countries, whether these countries are permissive or not. **Interpretation:** UK end-of-life decision-making is particularly collegiate and reflects caution about actions that significantly shorten life. A culture of sharing decisions with patients and relatives is also evident. *Palliative Medicine* 2006; **20**: 653–659

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

Introduction

The frequency of end-of-life decisions (ELDs) in UK medical practice in 2004 was reported in an earlier paper.¹ The proportion of UK deaths involving an ELD were: (i) voluntary euthanasia 0.16% (0–0.36); (ii) physician-assisted suicide 0.00%; (iii) ending of life without an explicit request from patient 0.33% (0–0.76); (iv) alleviation of symptoms with possibly life shortening effect 32.8% (28.1–37.6); and (v) non-treatment decisions 30.3% (26.0–34.6). Voluntary euthanasia and physician-assisted suicide were significantly less frequent than in the Netherlands and Australia; physician-assisted suicide was also less frequent than Switzerland. Ending life without an explicit request from the patient was less frequent than in Belgium and Australia. A comparison of UK and New Zealand general practitioners showed lower rates of the fourth and fifth ELDs in the UK. The fifth ELD (involving the withdrawal or withholding of treatment) was more common than in most other European countries.

It was suggested that the lower relative rate of ELDs involving doctor-assisted dying in the UK, and the relatively high rate of non-treatment decisions may reflect a culture of medical decision-making informed by a palliative care philosophy.

The present paper reports further results from the same survey data set, indicating the character of ELDs in

the UK, in particular the degree to which the five reported types of acts and omissions were felt to have shortened life, and whether they were discussed with patients, relatives and others, such as medical or nursing colleagues. This is important, since those who argue for the legalization of euthanasia may claim that prohibition results in secretive medical decision-making. Conversely, those who argue against legalization may be concerned about permissiveness leading to an inappropriate readiness to shorten life. Clearly, the optimum situation is one where there are underlying inhibitions about shortening life inappropriately, together with high levels of shared decision-making. The present paper, therefore, assesses the degree to which UK medical practice achieves this optimum state.

Comparison is made with other countries where the same survey has been carried out, chiefly six European countries,² and Australia.³ The focus of these comparisons is to examine the effect on ELDs of differing degrees of national permissiveness regarding medical involvement in actively ending life. Permissive cultures (such as the Netherlands, Belgium or Switzerland) involve both readiness to shorten life by longer times, and greater readiness to discuss ELDs with patients and relatives.² Doctors in non-permissive cultures (eg, Italy, Denmark or Sweden) are unlikely to report that ELDs shorten life significantly, and are less likely to report discussions with patients and relatives.² This paper assesses the degree to which UK ELDs are characteristic of permissive or non-permissive cultures.

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Methods

These are reported more fully elsewhere,¹ so a summary is given here.

Questionnaire and sampling

The questionnaire used for the Australian study,³ which had been translated from the original Dutch into English, was used (with minor modifications for the UK context). The European 'six countries' survey,² also used this questionnaire, though in this survey, sampling of deaths was from death certificates. Following the Australian methodology, respondents were asked about the care of the last death attended by the responding doctor, rather than sampling from death certificates. In addition to questions about the kinds of ELDs taken, doctors were asked to estimate the length of time by which the patient's life was shortened and whether and with whom the decision was discussed. They were also asked to estimate the patient's competence to take part in such discussions. Relevant questions are shown in Box 1.

Box 1: Questions asked about end of life decisions

In your estimation, how much was the patient's life shortened by the last mentioned act or omission? (More than six months/one to six months/one to four weeks/between one day and one week/ <24 hours/life was probably not shortened at all)

Did you or a colleague discuss with the patient the (possible) hastening of the end of the patients' life by this last mentioned act or omission?

Did you consider the patient capable of assessing his/her situation and making a decision about it adequately?

Did you or a colleague discuss with anybody else the (possible) hastening of the end of the patient's life before it was decided to take the last mentioned act or omission (please fill in as many answers as apply)? (with one or more medical colleagues/nursing staff or other caregivers/by partners or relatives of the patient/someone else/nobody).

A random sample of 1000 general practitioners and 1000 hospital specialists listed on Binley's database (www.binleys.com) of all working UK medical practitioners (updated in September 2004) were sent questionnaires, with two follow-up reminders, between October and December 2004. Analysis for this paper is based on an estimated response rate of 53% (857/1612), excluding cases where doctors had left their posts and, therefore, did not receive the questionnaire. Results reported in this paper are weighted to adjust for differences in the overall numbers of general practitioners and hospital specialists in the population of UK doctors. 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. This paper reports findings for the 417 cases where an ELD was reported. These included euthanasia, physician-assisted suicide, withholding and withdrawing treatment, and providing treatment to relieve suffering in the knowledge that this treatment might contribute to the ending of life.

Analysis

The survey allows for extrapolation from doctors' replies to the population of UK deaths, adjusting for the fact that different doctors report attending different numbers of deaths. This method was first used in the Australian implementation of the survey,³ and 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.
- 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,³ percentages of deaths and corresponding confidence intervals were calculated by treating the procedure as equivalent to cluster sampling with clusters of different sizes.⁴ 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 for UK data in Tables 1, 3 and 4.)

For results reporting on the proportion of doctors, percentages and confidence intervals were calculated using standard formulae applicable to simple random sampling (as in Tables 2 and 5).

The permissive/non-permissive dichotomy was constructed after a visual inspection of published data in the European six countries study,^{2,5} suggested a systematic difference between these two types of country. The theoretical justification for this derived variable,⁶ is as follows. Countries regarded for this analysis as 'permissive' include the Netherlands (where euthanasia and physician-assisted suicide have been permitted since 1984 and have been legal since April 2002) and Switzerland, where assisted-suicide has been legal since 1941. Also included in this group is Belgium, where euthanasia was made legal in May 2002, shortly after the European 'six countries' survey,² was completed. Belgium was included in this group on the grounds that the climate of opinion in a country shortly before such

Table 1 Estimated shortening of life: UK compared with six European countries;^a percentage of deaths and 95% CI^b

	Permissive countries	UK	Non-permissive countries
No. of deaths (100%)	5143	(12 915*)	2731
<1 week	58.6 (57.3–60.0)	87.7 (82.1–93.2)	80.7 (79.2–82.1)
One week to one month	35.6 (34.3–37.0)	8.2 (3.7–12.7)	18.5 (17.0–19.9)
More than one month	5.4 (4.8–6.1)	4.1 (0.2–7.9)	0.9 (0.5–1.2)

^aNon-UK data calculated from van der Heide *et al.*²; Table 3.

^bCases excluded where respondent could not say whether life was shortened.

*Extrapolated from 359 cases.

Boldface denotes UK is significantly lower; italics denotes UK is significantly higher.

legalization is likely to have been relatively permissive. Countries regarded as 'non-permissive' are Italy, Denmark and Sweden. Australia (Tables 2 and 5) is also a non-permissive country.

Where the UK is compared with other European countries (as in Tables 1, 3 and 4), data from the three permissive and the three non-permissive countries are grouped together. Data from countries other than the UK are calculated from tables appearing in the published reports of those surveys,^{2,3} which, in some cases, involved calculating raw numbers from reported percentages. Following the procedure outlined by the original authors of the 'six countries' study,⁵ when combining data from different countries, a weight was applied to these groupings, which was the inverse of the weighted number of deaths studied in each country in the group of three. This adjusts for the fact that the sample in each country was of a slightly different size.

Judgements of the statistical significance of comparisons between countries are based on whether 95% confidence intervals overlap rather than on χ^2 - or *t*-test estimates of significance. This is conservative in relation to accepting a comparison as statistically significant, since it sets a level of significance below $P=0.05$. This is done because cluster sampling (which applies to the extrapolated estimates of UK deaths) widens confidence intervals, so that application of χ^2 - or *t*-tests of difference is not straightforward. Although it would be valid to apply these tests to Tables 2 and 5, since these involve doctors not deaths, this would then have the effect of

making the level of significance for these tables more permissive than for the other tables.

Results

Shortening of life

Table 1 shows that doctors in non-permissive countries are significantly less willing than those in permissive countries to state that their actions shortened life by longer time periods. There are no significant differences between UK doctors and doctors in other countries for the rare event of shortening a patient's life by an estimated time of more than one month, something which was carried out by a non-treatment decision (ie, withdrawing or withholding treatment) in all of the UK cases. UK doctors, though, are less likely than doctors in other countries (whether permissive or non-permissive) to say that they shortened life by between a week and a month. Compared with permissive countries, UK doctors are more likely to say that they shortened life by less than a week. Table 2 presents a comparison with Australia, showing that UK doctors are more likely than Australian doctors to say that life was shortened by less than a week.

Thus, UK doctors are particularly unlikely to report that their decisions shortened life by more than a few days, if at all. In this respect, UK doctors' decisions fit in with, and even exceed, the profile of doctors' decisions in non-permissive countries.

Judgements of competence and discussion of ELDs

The first part of Table 3 shows that doctors in non-permissive countries are more likely than those in permissive countries to say that they did not know whether patients were competent, and to judge their patients to be not competent. They are less likely to judge their patients competent. UK doctors are particularly likely to say that they knew whether their patients were competent or not. Compared to doctors in permissive countries, they record more judgements of patients as not competent. Compared with doctors in non-permissive countries, UK doctors are more likely to judge patients competent.

Table 2 Estimated shortening of life: UK compared with Australia;^a percentage of doctors and 95% CI^b

	UK (2004)	Australia (1996)
No. of doctors (100%)	359	701
<1 week	91.1 (88.0–94.2)	84.6 (81.9–87.3)
One week to one month	6.1 (3.5–8.7)	10.0 (7.8–12.2)
More than one month	2.8 (1.0–4.6)	5.4 (3.7–7.1)

^aAustralian data calculated from Kuhse *et al.*³; Table 3.

^bCases excluded where respondent could not say whether life was shortened.

Italics denotes UK is significantly higher.

Table 3 Judgements of patient competence and discussions with patients and relatives: UK compared with six European countries; percentage of deaths and 95% CI^a

	Permissive countries	UK	Non-permissive countries
<i>No. of deaths (100%)</i>	5763	(14 209*)	3456
Competent	30.3 (29.1–31.4)	24.4 (18.0–30.8)	16.2 (15.0–17.4)
Not competent	57.0 (55.7–58.3)	67.6 (60.8–74.4)	60.5 (58.9–62.1)
Don't know if competent	12.7 (11.9–13.6)	8.0 (4.5–11.5)	23.3 (21.9–24.7)
<i>All patients where a judgement of competence was reported (=100%)</i>	5029	(13 077**)	2605
Discussed with patient	37.0 (35.6–38.3)	34.3 (26.2–42.4)	15.8 (14.5–17.3)
Not discussed with patient but patient had ever expressed wish	11.6 (10.7–12.5)	8.6 (4.9–12.4)	10.4 (9.3–11.6)
Discussed with relatives	76.2 (75.0–77.3)	57.8 (49.7–66.0)	44.3 (42.4–46.2)
Not discussed with patient or relatives	17.6 (16.5–18.6)	30.3 (23.0–37.6)	51.2 (49.3–53.1)
<i>Patient competent (=100%)</i>	1744	(3466***)	560
Discussed with patient	81.0 (79.0–87.1)	69.0 (57.3–80.7)	49.5 (45.4–53.7)
Not discussed with patient but patient had ever expressed wish	4.4 (3.5–5.3)	7.4 (0.1–14.6)	9.0 (6.7–11.4)
Discussed with relatives	75.4 (73.1–77.7)	43.7 (28.9–58.4)	45.6 (41.5–49.8)
Not discussed with patient or relatives	11.4 (9.9–12.9)	20.7 (10.6–30.9)	42.5 (38.4–46.6)
<i>Patient not competent (=100%)</i>	3285	(9605****)	2090
Discussed with patient	12.5 (11.3–13.6)	21.8 (12.9–30.7)	6.8 (5.7–7.9)
Not discussed with patient but patient had ever expressed wish	15.4 (14.1–16.7)	9.1 (4.8–13.4)	10.8 (9.5–12.1)
Discussed with relatives	76.6 (75.1–78.0)	63.0 (53.6–72.4)	43.9 (41.8–46.1)
Not discussed with patient or relatives	20.8 (19.4–22.2)	33.8 (24.7–42.9)	53.5 (51.3–55.6)

*Extrapolated from 417 cases.

**Extrapolated from 353 cases.

***Extrapolated from 117 cases.

****Extrapolated from 236 cases.

^aNon-UK data calculated from van der Heide *et al.*²; Table 4.

Boldface denotes UK is significantly lower; italics denotes UK is significantly higher.

The second part of Table 3 (all patients where a judgement of competence was reported) shows further that doctors in permissive countries are significantly more likely, than doctors in non-permissive countries, to say that they discussed decisions with patients and relatives. Conversely, doctors in non-permissive countries are significantly more likely to indicate that they discussed their decision with neither patient nor relative.

This second part of Table 3 shows that when compared with doctors in non-permissive countries, UK doctors are more likely to have discussed the decision with the patient or with relatives, and are less likely than doctors in non-permissive countries, to have discussed the decision with

neither. The third and fourth parts of Table 3 show that these differences hold true when non-competent patients are examined separately, and with the exception of discussions with relatives, for competent patients as well.

When compared with doctors in permissive countries, UK doctors are less likely to have discussed their decision with relatives, and this holds true when competent and non-competent patients are considered separately. UK doctors are more likely than doctors in these permissive countries to say that they discussed the decision with neither patient nor relative.

This suggests that, although the UK is a non-permissive country, UK doctors do not share the same

Table 4 Discussion with other doctors and nurses: UK compared with six European countries; percentage of deaths and 95% CI^a

	Permissive countries	UK	Non-permissive countries
<i>No. of deaths (100%)</i>	5763	(14 209*)	3456
Discussed with one or more medical colleagues	40.1 (39.7–42.2)	52.2 (44.6–59.8)	18.1 (16.8–19.3)
Nursing staff	47.3 (46.0–48.6)	46.7 (39.0–54.4)	28.5 (27.0–30.0)

*Extrapolated from 417 cases.

^aNon-UK data calculated from van der Heide *et al.*²; Table 4.

Boldface denotes UK is significantly lower; italics denotes UK is significantly higher.

Table 5 Judgements of patient competence and discussions with patients, relatives, doctors and nurses: UK and Australia compared; percentage of doctors and 95% CI^a

	UK (2004)	Australia (1996)
<i>(a) Judgements of competence</i>		
No. of doctors (100%)	417	800
Competent	28.1 (23.8–32.4)	38.9 (35.5–42.26)
Not competent	56.6 (51.8–61.4)	<i>48.0 (44.5–51.4)</i>
Don't know if competent	15.1 (11.7–18.5)	13.1 (10.8–15.5)
<i>(b) Discussions with doctors, nurses and relatives</i>		
No. of doctors (100%)	417	800
One or more medical colleagues	40.5 (35.8–45.2)	<i>28.3 (25.1–31.4)</i>
Nursing staff	39.8 (35.1–44.5)	<i>31.6 (28.4–34.9)</i>
Relatives	46.3 (41.5–51.1)	46.9 (43.4–50.3)
<i>(c) Discussions with patients</i>		
<i>Patient competent</i>		
No. of doctors (100%)	117	311
Discussed with patient or patient had wished	61.5 (52.7–70.4)	73.6 (68.7–78.5)
<i>Patient not competent</i>		
No. of doctors (100%)	236	384
Discussed with patient or patient had wished	29.2 (23.4–35.0)	<i>8.3 (5.6–11.1)</i>
<i>All patients where a judgement of competence was reported</i>		
No. of doctors (100%)	353	695
Discussed with patient or patient had wished	39.9 (34.8–45.0)	37.6 (34.0–41.2)

^aAustralian data calculated from Kuhse *et al.*³; Table 3. Boldface denotes UK is significantly lower; italics denotes UK is significantly higher.

level of reluctance of doctors in such countries to discuss decisions with patients and relatives. However, UK doctors fall short of those in permissive countries in overall willingness to discuss decisions, and in willingness to discuss with relatives. Thus, the UK is somewhere between permissive and non-permissive countries in the openness with which decisions are discussed with patients and relatives.

Table 4 shows that doctors in permissive countries are more likely, than those in non-permissive countries, to say that they discussed their decision with other doctors and with nurses. UK doctors are similar to the doctors in permissive countries in this respect, even exceeding them in the proportion reporting discussions with medical colleagues.

Table 5 shows that UK doctors are less likely than Australian doctors to report patients to be competent, more likely to report them not competent. They are more likely to report discussions with medical colleagues and nursing staff and, where patients were judged not competent, were more likely to say that they had discussed their action or omission with the patient, or that the patient had, at some point, expressed a wish about this.

Competence and discussion of ELDs: qualitative data analysis

Doctors were invited to write comments on their questionnaires and some of these provide insights into some of the situations that lay behind the statistical data reported. For example, two doctors described situations where they judged the patient competent, but had not discussed the ELD with the patient or relatives:

Attempts to discuss end of life decisions appeared to me to be blocked by the patient. He was focused solely on treatment to improve his symptoms and give him more time alive. He knew his two conditions were not curable. (103)

I am involved with patients on dialysis therapy and this can sometimes prolong life in patients where they perhaps do not have what is perceived by themselves or ourselves as a reasonable quality of life and on occasion they are so obtunded it is difficult to discuss withdrawal of therapy with them/have a rational discussion. Sometimes there is pressure from family to continue what is futile treatment, given other underlying morbidity. (853)

In a further case involving a competent patient, where relatives rather than the patient were consulted, the doctor indicated that the patient had previously made his wishes clear:

Family indicated patient was well aware of his illness and thought that actively discussing it with patient would be upsetting. (326)

Sometimes discussions with all parties resulted in a fully shared decision:

A decision was made with patient, her daughter and the haematologist that no further transfusions would be given, as her quality of life was so poor. She died within a week. (282)

But in one case doubts remained about the degree to which the patient had felt free to decide what she wanted:

The patient was an old lady in an old people's home who ... refused onward referral or any investigations. Her relatives agreed with her. I would have preferred a few simple investigations as I felt there was a slight chance that it may have been something very simple to rectify (infection). She still refused. I was slightly concerned that the relatives may have influenced her into making this decision for the wrong reasons. (eg, it would be easier for them if she died quickly.) (62)

In some cases where a doctor had indicated that a patient was 'not competent', it is clear that consideration of the patients' feelings had contributed to this judgement.

With the fact that patient had very advanced cancer disease with metastasis and patient is on lot of opioid analgesia ... it is inappropriate to discuss with the patient; who is already aware that he is going to die. For this situation most of the time I ask relative including sons and daughters and brother and sisters, there response is most of the time is please do not discuss with my mother or father etc. (375)

When a patient is confused in the terminal illness but also showing signs of pain and distress I am sure it is appropriate to treat symptoms but not to add to distress by attempting to discuss Do Not Resuscitate decisions. (792)

Discussion

The results show that UK doctors are similar to doctors in permissive countries in one respect (discussing decisions), and similar to doctors in non-permissive countries in another respect (shortening life).

On the one hand, UK doctors are particularly unlikely to report that their decisions shorten life by more than a few days when compared to doctors making ELDs in other countries, whether these countries are permissive or not. In reporting this, though, UK doctors are closest to doctors in non-permissive countries. Together with the earlier report from this study,¹ indicating a relative low rate of decisions involving euthanasia or physician-assisted suicide, this suggests UK doctors are particularly cautious.

On the other hand, willingness to discuss ELDs with patients and relatives is relatively high in the UK, and in this respect, the UK (being a 'non-permissive' country) differs from other non-permissive countries. However, this willingness is not as high in the UK as it is in the permissive countries. Instead, UK doctors stand out as being particularly likely to say that they consulted other doctors and nurses about ELDs and, in the case of discussions with medical colleagues, exceed doctors in permissive countries in the rate of such consultations.

Given that permissiveness, in general, appears to encourage more widespread discussion and a less cautious approach to shortening life by a considerable amount of time, it is perhaps surprising that the UK (as a non-permissive country) exhibits these contrasting features. The cautiousness about shortening life, and the relatively high concern to discuss decisions with colleagues may indicate a particularly collegiate approach to decision-making, coupled with a heightened awareness of potential scrutiny. There is also a long-standing commitment in UK medical culture to shared decision-making, and this may explain why UK doctors are more willing than doctors in other non-permissive countries to discuss ELDs with patients and relatives. The lower UK rate of

reported discussions with relatives, when compared with permissive countries, may reflect a UK emphasis on only consulting relatives after patients' permission for this has been given.

Although respondents knew that their replies could not be traced back to them, it is possible that the reporting of the characteristics of ELDs may have been influenced by prevailing legal prohibitions. This may have led UK doctors to over-emphasize their caution and collegiality. On the other hand, such factors will also have applied in other non-permissive countries, so comparisons of the UK with those countries are not affected by this consideration.

Additionally, the representativeness of a sample of deaths drawn by asking doctors to recollect the last death they attended, compared with samples drawn from death certificates, may be questioned. Any future implementation of this survey should include questions about the age, gender and cause of death of the person whose death the respondent describes, in order that this may be evaluated. It is already known,¹ that the method underestimates the number of sudden and unexpected deaths, but this does not affect the present paper, since only non-sudden deaths that involved decisions are analysed. Methodological studies comparing the results of the two survey methods (recall of last patient versus death certificates) are desirable, since the recall method is far cheaper than the death certificate method, which is, in any case, not feasible in the UK because the use of death certificates for survey sampling is now highly restricted due to privacy legislation.

The qualitative data is a reminder of the complexity of these decisions and discussions. Doctors are involved in balancing a number of competing demands, from patients, relatives, colleagues and, ultimately, legal requirements. It is not always solely a matter for them to decide whether to discuss an ELD with a patient, given that some patients and relatives resist such discussions. Judgements of 'competence' too, are not necessarily straightforward and involve assessments of emotional readiness as well as cognitive capacity. A study involving interviews with attending doctors could gather better information about such contextual detail.

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