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Short report

Changes in medical end-of-life practices during the legalization process of euthanasia in Belgium

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Abstract

Changes in medical practices during transitions in regulating healthcare are rarely investigated. In this study, we investigated changes in medical end-of-life decisions with a possible or certain life-shortening effect (ELDs) that occurred during the legalization process of euthanasia in Belgium. We took representative random samples from deaths reported to registries in Flanders, Belgium in 1998 ($n = 3999$) at the beginning of the process and in 2001 ($N = 5005$), at the end of the process. The reporting physicians received an anonymous mail questionnaire about possible ELDs preceding the death involved. We found no significant shifts in the epidemiology of diseases between 1998 and 2001. The overall incidence of ELDs did not change. The incidence decreased for euthanasia, administering life-ending drugs without patient's explicit request, and alleviation of pain and symptoms with life-shortening co-intention. Incidence increased for alleviation of pain and symptom without life-shortening intention, and remained stable for non-treatment decisions. All decisions in 2001 were more often discussed with patients, their relatives and nurses. In 2001, continuous deep sedation was reported in 8.3% of deaths. We can conclude that physicians' end-of-life practices have substantially changed during the short but tumultuous legalization process of euthanasia in Belgium. Although follow-up research is needed to investigate the continuance of these changes, it is important for policy makers to keep in mind that social factors related to transitions in healthcare regulation may play an important role in the physicians' actual behaviour.

Keywords: Belgium; Euthanasia; Legalization; End-of-life decisions; Health policy

Introduction

In several countries, regulation of physician-assisted suicide and the role of medical care in the process of death and dying are increasingly discussed (Charatan, 2006; Doyal & Doyal, 2001; Finlay, Wheatley, & Izdebski, 2005). However, until now, only the Netherlands and Belgium have

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formally legalized euthanasia, both in 2002 (Deliens & van der Wal, 2003). In the Netherlands, the legalization of euthanasia was the outcome of a social process, lasting about two decades (Griffiths, Weyers, & Blood, 1998), and with active involvement of the Parliament, the judicial system, healthcare professionals, patients' lobbying groups, and ethicists (Weyers, 2001). The Dutch government also repeatedly commissioned researchers to investigate the incidence of euthanasia and other medical end-of-life decisions with a possible or certain life-shortening effect (ELDs) (van der Heide et al., 2003; van der Maas et al., 1996). In Belgium, the process of legalization of euthanasia, preceded by a debate in 1997 in the Belgian Council for Bioethics (Adams, 2001) was actually put on the political agenda in 1999, resulting in parliamentary hearings in the Senate in 2000 (Broeckaert, 2001). A vigorous debate followed in the media, and among healthcare professional organizations (Schotsmans & Broeckaert, 1999; Weber, 2001). On May 2002, the euthanasia law was already approved, allowing physicians to administer lethal drugs to adult patients under strict conditions of carefulness (Wet betreffende euthanasie 28 mei 2002, 2002). In contrast with the Netherlands, the legalization process in Belgium was thus finalized rather quickly, without broad professional consensus, and accompanied by an intensive political and social debate.

The aim of this paper is to investigate possible changes in medical end-of-life decisions with a possible or certain life-shortening effect (ELDs) occurring during such tumultuous transition period, and to look for possible explanations.

Methods

Study design

We compared two identical nationwide death certificate studies establishing the incidence and characteristics of ELDs in Flanders, Belgium, one conducted in 1998, before the real debate on the legalization of euthanasia started, and the other in 2001 at the end of the debate (Deliens et al., 2000; van der Heide et al., 2003). In both studies, we took a random sample ($N = 3999$ in 1998 and $N = 5005$ in 2001) of all deaths from the official death registries. Physicians who had signed a sampled death certificate received a self-administered mail questionnaire concerning the death involved. Up to three follow-up mailings were sent in case of non-response. All physicians were explicitly asked to return the questionnaire completely anonymously, and a complex mailing procedure, involving a legal attorney, was developed, to guarantee total anonymity for all patients and physicians involved (Verstraeten, Vander Stichele, & Deliens, 2001).

Questionnaires

In the first question we asked the physician whether or not the patient died 'suddenly and unexpectedly', precluding any ELD. For the remaining cases, we asked whether or not an ELD had occurred, and if yes, what type of ELD. The type of the ELD was determined by a predefined analysis scheme of answers to several non-leading questions (e.g. the word 'euthanasia' was never used). The following main ELD-categories were distinguished: non-treatment decisions, alleviation of pain and symptoms, physician-assisted suicide, euthanasia (defined as 'administering lethal drugs by a physician on the patient's explicit request'), and using life-ending drugs without the patient's explicit request. Furthermore, we investigated the characteristics of the decision-making process, e.g. was the decision taken after discussion with the patient, family members or other healthcare professionals. In 2001, we added one additional question about whether or not the patient was kept in continuous deep sedation until death.

Data analysis

In total we received 1925 (48%) of the 3999 questionnaires mailed in 1998 and 2950 (59%) of the 5005 questionnaires in 2001. We combined the databases into one common data file with consistent coding of variables, and weighted the data for disproportional stratification and non-response. Significance of distribution and incidence differences between the 2 years was tested by the Fisher's Exact test (5% α-level). To test whether differences in ELD incidences were related to the year of dying independent from other variables, we additionally calculated adjusted odds ratios (with 95%CI) by performing for each type of ELD a multivariate regression analysis. All calculations were performed using the statistical packages StatXact v. 6.0 or SPSS v. 12.0.

For more detailed information on the sampling and mailing procedure, the questionnaire and ELD-classification system, and the weighting of the dataset,

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we refer to the two earlier mentioned publications (Deliens et al., 2000; van der Heide et al., 2003).

Results

Shifts in population mortality

In 1998 as well as in 2001, the annual mortality rate in Flanders was 0.9% for a stable population of six million inhabitants. The distribution of deaths' characteristics (age, sex, educational level, cause of death) was very similar in both years. A quarter of all people died at home. Compared with 1998, somewhat less people in 2001 died in a hospital (56% versus 50%) and somewhat more in a nursing home (17% versus 21%) (not shown in table).

Incidence and characteristics of end-of-life decisions

The proportion of sudden deaths, non-sudden deaths with or without ELDs remained unchanged in the 2 years (Table 1). The overall incidence of drug use with the explicit intention to end the patient's life decreased from 4.4% of all deaths in 1998 to 1.8% in 2001: euthanasia from 1.1% to 0.3%, and the use of life-ending drugs without the patient's explicit request from 3.2% to 1.5%. The alleviation of suffering with a co-intention to shorten life also decreased from 5.3% to 2.8% while it increased from 13.2% to 19.2% when life shortening was taken into account but not co-intended. The incidence of non-treatment decisions with possible life-shortening effect did not significantly vary between the 2 years. The adjusted odds ratios in the logistic regression analyses confirmed that these changes were related to the year of dying independent from other variables. No differences between both years were found in the estimated lifetime shortening due to ELDs, and in the distribution of patient characteristics within each category of ELD (not shown in Table 1).

Decision-making process

There was a tendency in all ELDs to discuss the decision with competent patients more often in 2001 than in 1998, except for non-treatment decisions (Table 2). Family members were more often involved in all ELDs in 2001, especially for alleviation of suffering with a life-shortening co-intention (96% versus 71%) and non-treatment decisions (79% versus 60%). For incompetent patients, ELDs made without discussion with either patient or family were much less frequently reported in 2001 (22%) than in 1998 (44%). Family members were more often involved in 2001 than in 1998 (77%

Table 1
Frequency of end-of-life decisions in Flanders, Belgium 1998 and 2001

Number of deaths per year	Flanders 1998 56,354 (%)	Flanders 2001 55,793 (%)	*P*-value†	Significant adjusted odds ratio (95% CI)‡
Sudden deaths, ELD[a] not possible	33.3	34.1	0.53	—
ELD possible, but not made	27.4	27.5	1.00	—
All deaths with an ELD	39.3	38.4	0.52	—
The use of drugs with the explicit intention to end the patient's life	4.4	1.8	<0.001	0.412 (0.290–0.584)
Euthanasia	1.1	0.3	<0.001	0.260 (0.118–0.573)
Physician-assisted suicide	0.1	0.01	0.25	—
Life ending without the patient's explicit request	3.2	1.5	<0.001	0.478 (0.323–0.708)
Alleviation of pain and symptoms with possible life-shortening effect	18.5	22.0	0.001	1.331 (1.140–1.554)
Taking into account life shortening	13.2	19.2	<0.001	1.689 (1.425–2.001)
Life shortening co-intended	5.3	2.8	<0.001	0.535 (0.397–0.721)
Non-treatment decisions with possible life-shortening effect	16.4	14.6	0.05	—

Data have been adjusted for stratification (2001) and weighted for non-response (1998 and 2001); †Significance of bivariate difference in ELD-frequencies between 1998 and 2001 was tested by Fisher's Exact test and using statistical package SPSS v. 12.0; ‡ Significant odds ratios for year of death (1998 = reference group), adjusted for patient characteristics (age, sex, marital status, educational level, and cause of death) and for place of death (at home, in hospital, in nursing home, elsewhere), calculated by logistic regression, forward stepwise conditional methods and using statistical package SPSS v. 12.0.

[a] ELDs: medical end-of-life decisions with a possible or certain life-shortening effect.

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Table 2
Decision-making process preceding end-of-life decisions in Flanders, Belgium 1998–2001

End-of-life decisions[a]	Euthanasia		LAWER		APS1		APS2		NTD		All ELDs	
Year	1998	2001	1998	2001	1998	2001	1998	2001	1998	2001	1998	2001
Number of cases studied	22	17	60	56	235	731	97	115	303	431	720	1351
Patient was competent†	*100%*	*100%*	*10%*	*20%*	*32%*	*32%*	*29%*	*32%*	*15%*	*16%*	*25%*	*26%*
Decision discussed with patient	100	100	67	78	47	57	75	88	83	75	68	67
Not discussed, but patient had ever expressed wish	—	—	33	11	13	7	14	8	2	11	9	8
Decision discussed with patient's relatives	62	100	67	89	56	61	**71**	**96**	**60**	**79**	**60**	**71**
Decision not discussed with patient or relatives	—	—	—	11	36	31	7	—	9	11	19	21
Discussion with:												
Other physician	55	63	33	44	49	46	46	72	57	40	50	48
Nursing staff	32	56	29	33	**37**	**54**	**46**	**80**	45	60	**40**	**58**
No other caregiver	5	13	33	33	24	27	11	8	13	18	17	23
Patient was incompetent †	—	—	*90%*	*80%*	*68%*	*68%*	*71%*	*68%*	*85%*	*84%*	*75%*	*74%*
Decision discussed with patient	—	—	**4**	**21**	**1**	**15**	4	15	**6**	**14**	**4**	**15**
Not discussed, but patient had ever expressed wish	—	—	27	17	13	12	20	19	8	3	13	13
Decision discussed with patient's relatives	—	—	**56**	**91**	**48**	**66**	77	87	**53**	**83**	**55**	**77**
Decision not discussed with patient or relatives	—	—	**44**	**6**	**52**	**32**	22	9	**46**	**16**	**44**	**22**
Discussion with:												
Other physician	—	—	47	66	42	43	45	49	55	53	49	49
Nursing staff	—	—	**45**	**77**	**46**	**60**	**49**	**72**	**46**	**69**	**46**	**66**
No other caregiver	—	—	15	3	27	24	13	6	**15**	**10**	18	15

Data are expressed as weighted % unless otherwise stated. Percentages are adjusted for stratification (2001) and weighted for non-response (1998 and 2001); Significant differences in frequencies between cases in 1998 and in 2001 are printed in bold and underlined (with α-level ⩽0.05); Significance was tested by Fisher's Exact test, and using the statistical package SPSS v. 12.0.

[a] LAWER = 'life-ending acts without explicit request': the administration of (lethal) drugs with the explicit intention of hastening the patient' s death without his/her explicit request; APS1 = alleviation of pain and symptoms with possible life-shortening effect, life-shortening not intended; APS2 = alleviation of pain and symptoms with possible life-shortening effect, life-shortening co-intended; NTD = non treatment decision with possible life-shortening effect. †Competence of the patient was unknown, because data missing for 10 APS1-cases, four APS2-cases, and four NTD-cases in 1998 and 135 APS1-cases, six APS2-cases, and 27 NTD-cases in 2001.

versus 55%). Nurses were more often consulted in 2001 than in 1998, both for competent (58% versus 40%) and incompetent (66% versus 46%) patients.

Continuous deep sedation

In 8.2% of all deaths in 2001 (no data available for 1998), physicians reported to have sedated patients until death, using drugs such as benzodiazepines or barbiturates (not shown in table). In 3.2% of all deaths, this continuous deep sedation was practiced while forgoing the administration of food and/or fluids. In 3.6% of all deaths it was practiced without any intention of the physician to hasten the patient's death.

Discussion

We observed remarkable shifts within medical end-of-life practices between early 1998 when the legalization process of euthanasia in Belgium started and late 2001 just before the end of this process. First, in 2001 there was a substantial reduction in the incidence of euthanasia, the use of life-ending drugs without the patient's explicit request and the alleviation of suffering with the co-intention to hasten deaths, while the incidence increased for alleviation of suffering taking into account but without life-shortening co-intention. Second, physicians acted more carefully in the decision-making process, as patients, their family members, and nurses were more often involved. And third, continuous deep sedation rose to an incidence of 8.2% in 2001. We think these shifts can, at least partly, be explained by social developments, closely related to the euthanasia legalization process.

The period of 3 years separating the two surveys was long enough to detect possible changes in medical practices, but probably too short to be influenced by significant shifts in the demographics of the population, epidemiology of diseases, or by

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generation effects in the physicians' attitudes or shifts in the general level of secularization. In both studies, we used the same study design, guaranteeing strict anonymity, and with an almost identical questionnaire, data collection method, coding and analysis procedure. There are also some limitations to our study. All findings are exclusively based on information provided by physicians, and because this study was not designed to determine causal inferences only plausible hypotheses could be put forward.

We see a number of plausible explanations for the relevant changes, closely related to the euthanasia legalization process. First, the decrease in incidence of medical decisions with a (co-)intended life-shortening effect may be caused by fear for judicial action among physicians in 2001. Within the context of an increased public and political attention for medical end-of-life issues during the legalization process, the judiciary in Belgium initiated, after several decades of inactivity in this field, a number of criminal investigations concerning life ending in a medical context (Dagblad De Standaard Online, 2006). This may also in part explain the tendency to seek consensus more intensely with close relatives of the patients and with other healthcare professionals whenever a decision to hasten death had to be made.

Second, this increase in carefulness in the decision-making process may also be related to the growing readiness among physicians to improve the quality of the remaining life, to maintain dignity for patients and their families, and to actively involve patients and/or their family (Morrison, Siu, Leipzig, Cassel, & Meier, 2000). Also the growing importance in society of self-determination by patients may have led to an increased expectation and readiness among patients, family members and nurses to participate in these decisions. Timely discussion with terminally ill patients about their needs and preferences in end-of-life care may also have prevented physicians from using life-ending drugs without the patient's explicit request. This practice occurred fairly often in 1998, mostly in postponed decisions by physicians and nurses confronted with incompetent patients in an irreversible, unbearable, and painful situation (van der Wal, 1993).

Third, although no data were available on the incidence of continuous deep sedation before and up to 1998, its use was probably limited to a small number of pioneering centres in Flanders. Since then, this technique has been strongly promoted for patients with refractory symptoms, especially by healthcare professionals opposed to the legalization of euthanasia. However, in more than half of the found cases in our study, the physician had also the intention to hasten the patient's death, and it is not yet known to what extent this sedation is performed in competent or incompetent patients, and with or without their explicit request. Also, the question remains to what extent this practice is used as an enhancement of palliative care, or rather as a technological fix for ethical and legal dilemmas in dealing with patients requesting euthanasia (Matersvedt & Kaasa, 2000).

To conclude, in the Netherlands, until now the only other country where such comparisons were made, studies between 1990 and 2001 revealed that the continuing debate since several years about physician-assisted dying seemed to have resulted in a gradual stabilization of end-of-life practices (Onwuteaka-Phillipsen et al., 2003). In Belgium, on the contrary, changes observed between 1998 and 2001 were rather remarkable. Although follow-up research is needed to investigate the continuance of these changes, this study suggests that contextual social factors accompanying transitions in regulating healthcare may play a substantial role in the physicians' actual behaviour, especially when it concerns controversial medico-ethical issues, regulated in a rather short period. To guarantee continuity in qualitative care, it is important for healthcare policy makers to take this into account while introducing changes themselves or implementing changes of others.

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