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## Informatie aan de pers

Datum : 24 september 2004

Betreft : Verpleegkundigen hebben nood aan regelgeving bij euthanasie

### Regelgeving voor samenwerking tussen artsen en verpleegkundigen bij euthanasie en andere medische beslissingen rond het levenseinde is noodzakelijk

Er is nood aan professioneel ondersteunde regelgeving voor de samenwerking tussen artsen en verpleegkundigen bij het uitvoeren van euthanasie. Er moet eveneens werk gemaakt worden van een adequate en zorgvuldige communicatie tussen beide partijen bij alle levenseindebeslissingen. Dat blijkt uit de studie *'Involvement of nurses in physician-assisted dying'* van de onderzoeksgroep Zorg rond het Levenseinde van Prof dr Luc Deliens (VUB) in samenwerking met onderzoekers van de Universiteit Gent.

In 1998, vier jaar voor de invoering van de wet die euthanasie door artsen mogelijk maakte, kwamen reeds regelmatig situaties voor waar verpleegkundigen zelf dodelijke medicijnen toedienden aan patiënten: in 59% van alle euthanasiegevallen in instellingen en in 17% van deze in thuissituaties. Dit gebeurde steeds samen of in aanwezigheid van de verantwoordelijke arts, of binnen de context van een palliatief team. Voor het toedienen van levensbeëindigende middelen zonder uitdrukkelijk verzoek van de patiënt (meestal doodzieke, wilsonbekwame patiënten, niet meer in staat tot het uiten van een uitdrukkelijk verzoek) bedroegen de percentages respectievelijk 83% en 25%. In de thuissituatie gebeurde dit eveneens bijna steeds in aanwezigheid van een arts. In instellingsverband daarentegen was deze beslissing wel meestal op voorhand besproken met de arts, maar in meer dan de helft van deze gevallen was de arts niet aanwezig bij de uitvoering ervan. De onderzoekers stelden ook vast dat overleg tussen een arts en een verpleegkundige bij beslissingen rond het levenseinde slechts plaats had in één op twee beslissingen in de instellingen en in één op vijf beslissingen in de thuissituatie.

*"Ten tijde van deze studie waren verpleegkundigen in België weliswaar veelvuldig betrokken bij het toedienen van dodelijke medicijnen in levenseindebeslissingen, hun inbreng in het besluitvormingsproces voorafgaand aan levenseindebeslissingen in het algemeen (die voorkomen in 39% van alle overlijdens in Vlaanderen) was daarentegen eerder beperkt", stelt VUB-RUG-onderzoeker Johan Bilsen. "Het toedienen van dodelijke medicijnen aan patiënten door verpleegkundigen was op dat moment illegaal en is dat nog altijd, ondanks de Belgische euthanasiewet van 2002," aldus nog Johan Bilsen. "Om er voor te zorgen dat de wetgeving terzake wordt opgevolgd, maar ook om tussen arts en verpleegkundige het overleg en de communicatie over beslissingen rond het levenseinde te verdiepen en noodzakelijk te maken, is regelgeving nodig die door de beroepsgroepen wordt ondersteund en door de wet wordt bekrachtigd".*

De resultaten van de studie zijn gebaseerd op de gegevens van een schriftelijke postenquête bij artsen in Vlaanderen die overlijdensaktes tekenden. Uit de overlijdens van de eerste vier maanden van 1998 werd een representatieve steekproef van 4.000 sterfgevallen getrokken. De artsen die deze overlijdensaktes ondertekenden stuurden 1.925 vragenlijsten behoorlijk ingevuld terug naar de onderzoekers.

De VUB Onderzoeksgroep Zorg rond het Levenseinde van Prof. Luc Deliens is multidisciplinair samengesteld (artsen, verpleegkundigen, sociologen, psychologen, etc) en doet onderzoek naar palliatieve zorg en medische beslissingen rond het levenseinde. Hij onderhoudt een intense samenwerking met onderzoekers uit verschillende andere universiteiten in binnen- en buitenland.

De studie *'Involvement of nurses in physician-assisted dying'* (auteurs: Johan Bilsen, Robert Vander Stichele, Freddy Mortier en Luc Deliens ) werd gepubliceerd in het internationale tijdschrift *Journal of Advanced Nursing* 47(6), 583-591.

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## Involvement of nurses in physician-assisted dying

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### Involvement of nurses in physician-assisted dying

**Background.** Death in modern societies is often preceded by medical end-of-life decisions. Empirical research on these end-of-life decisions focuses predominantly on the physicians' role. Little is known about the role of other health care workers, especially that of nurses.

**Aim.** This paper reports the findings of a study that investigated how often nurses are consulted by physicians in the decision-making process preceding end-of-life decisions and how often nurses participate in administering lethal drugs in end-of-life decisions.

**Method.** Data were collected within a nationwide cross-sectional retrospective death certificate study in Flanders, the Dutch-speaking part of Belgium. We selected 3999 deaths, a 20% random sample of all those occurring during the first 4 months of 1998. Anonymous questionnaires were mailed to the physicians who signed the death certificates. Several questions concerned the involvement of nurses in end-of-life decisions.

**Results.** We received 1925 valid questionnaires. For all reported end-of-life decisions (39.3% of all deaths in Flanders), physicians provided information about the involvement of nurses. Physicians consulted at least one nurse in 52% of end-of-life decisions cases occurring in institutions, compared with 21.4% of such cases at home. Nurses administered lethal drugs in 58.8% of euthanasia cases occurring in institutions and in 17.2% at home. For cases in which life was ended without the patient's explicit request because they were too ill to do so, these percentages were respectively 82.7% and 25.2%. In institutions, nurses mostly administered drugs without the attendance of a physician who had prescribed the drugs.

**Conclusions.** Nurses in Belgium are largely involved in administering lethal drugs in end-of-life decisions, while their participation in the decision-making process is rather limited. To guarantee prudent practice in end-of-life decisions, we need clear guidelines, professionally supported and legally controlled, for the assignment of duties between physicians and nurses regarding the administration of lethal drugs to reflect current working practice. In addition, we need appropriate binding standards governing mutual communication about all end-of-life decisions.

**Keywords:** euthanasia, assisted suicide, end-of-life decisions, nurses, ethics

## Introduction

In modern industrialized societies, death and dying increasingly become institutionalized and medical issues (Corr 1998, Clark 2002, Evans & Walsh 2002). Health care professionals are increasingly confronted with decisions that have a direct or indirect impact on the survival time of the terminally ill (van der Maas *et al.* 1991, 1996, Kuhse *et al.* 1997, Meier *et al.* 1998, Deliens *et al.* 2000). Public and ethical debate about these end-of-life decisions (ELDs), scientific research, guidelines for prudent practice, and legislatures focus predominantly on the role of physicians, seemingly assuming that the tasks of other health care professionals are less important. Especially with regard to the nursing profession, this assumption can be questioned (Haisfield-Wolfe 1996, The 1997, Faber-Langendoen & Karlawish 2000). Along with physicians, nurses represent the largest group among health care professionals. They care for the patient on a daily basis, and often have a confidential and close relationship with the terminally ill and their next of kin.

In 2002, laws legalizing euthanasia by physicians under strict conditions officially came into force in Belgium (Belgian Law Gazette 2002) and the Netherlands (Dutch Law Gazette 2001). After the rejection of several proposals for a euthanasia bill in the 1980s and early 1990s, discussion in Belgium about possible legalisation of euthanasia was initiated by a new governmental coalition, installed in 1999, and changing the law was preceded by a 3-month period of hearings in the Senate and by extensive public debate (Broeckaert 2001). The study reported here is a nationwide death certificate study, conducted in Belgium in 1998, when euthanasia was still illegal. Administration of lethal drugs to patients by nurses was (and still is under the new euthanasia law) legally prohibited in any circumstance, and this has been confirmed by professional nursing guidelines (WVVV 2002). Physician–nurse relationships tend to be hierarchical in Belgium and medicines in general can only be prescribed, distributed and administered under medical supervision. Nurses have the right to refuse any participation in the performance of euthanasia.

In some countries, nurses' involvement in physician-assisted dying has been investigated through research on physicians' and nurses' attitudes and opinions or their reported participation in a hypothetical or last recalled ELD-case (Kuhse & Singer 1993, Asch 1996, Matzo & Emanuel 1997, Muller *et al.* 1997, Ferrell *et al.* 2000, Young & Ogden 2000, Asai *et al.* 2001, Ganzini *et al.* 2002). For the first time, we report reliable estimations of nurses' actual involvement in ELDs, on the basis of their reported participation in all ELDs occurring in a representative sample of deaths, in a country where euthanasia was a clandestine practice. We describe the frequency with which nurses were consulted by physicians before the ELDs, and the frequency with which they participated in administering lethal drugs in physician-assisted dying (euthanasia and life-ending acts without explicit request of the patients because they were too ill to do so).

## The study

### Aim

The aim of the study was to report the actual involvement of nurses in medical end-of-life decisions (ELDs). We investigated how often nurses were consulted by physicians in the decision-making process preceding ELDs, and how often nurses participated in administering lethal drugs in euthanasia and in 'life-ending acts without the patient's explicit request' because they were too ill to do so.

### Design

The data were collected through a retrospective cross-sectional death certificate study (Deliens *et al.* 2000). The unit of analysis was the sampled death case, and the information was given by the physician who signed the death certificate. The study was conducted in the Belgian sub-state of Flanders, which has a population of about 6 million inhabitants (60% of the Belgian population) and about 56 000 deaths/year.

## Sample

All deaths in Flanders are reported to the authorities by means of death certificates, signed by the attending physician. For this study, we selected all deaths of persons aged 1 year or older that had occurred during the first 4 months of 1998. The selected 20 362 death certificates were proportionally stratified for the five provinces of Flanders and by the month of death. We took a 20% random sample out of these certificates, and all physicians who signed the 3999 sampled certificates received one self-administered mail questionnaire per death (up to a maximum of five per physician). Response was further enhanced by conducting the survey by the principles of the Total Design Method (Dillman 1991). More information about the methodology and the mailing procedure has been reported elsewhere (Deliens *et al.* 2000).

## Questionnaire

### Terminology

The questionnaire was based on that used in the Dutch studies of 1990 and 1995 (van der Maas *et al.* 1991, 1996). In 1996 we conducted a pilot study ( $n = 489$ ) in the city of Hasselt, the capital of one of the five provinces of Flanders, Belgium, with 67 398 inhabitants and 970 deaths per year (Mortier *et al.* 2000). Following this pilot study (55% response rate), we added a few questions and made some minor changes in the phrasing of some sentences. The final questionnaire consisted of 51 questions about medical interventions with a possible life-shortening effect. The questions concerned the kind of intervention, its intention, and the preceding decision-making process. Words like 'euthanasia' or 'physician-assisted suicide' were not used because of possible confusion of terminology. Based on a combination of answers to different questions, the cases were classified according to the following categories of ELDs:

- Euthanasia (EUTH): administration of drugs with the explicit intention of ending the patient's life, at the patient's explicit request.
- Physician-assisted suicide (PAS): prescription or supplying of drugs with the explicit intention of enabling the patient to end their own life.
- Life-ending acts without request (LAWER): administration of drugs with the explicit intention of ending the patient's life, without their explicit request because they were too ill to do so.
- Alleviation of pain and symptoms (APS): intensifying the use of drugs to alleviate pain and symptoms in a potentially life-shortening way.

- Non-treatment decisions (NTD): withholding or withdrawing (potentially life-prolonging) treatment, with or without the explicit intention of hastening the patient's death.

### Involvement of nurses

Some questions in this questionnaire concerned the actual involvement of nurses in ELDs. First, to investigate the consultation of nurses by physicians before performing an ELD, we used answers of physicians to specific questions about the decision-making process preceding ELDs: 'Did you discuss the decision with someone else before making the decision?' Multiple answers were possible: 'a colleague physician, a nurse, family members, someone else, and nobody.' Secondly, to calculate figures for the direct participation of nurses in administering lethal drugs, we used answers of physicians to questions about the person(s) who administered the lethal drug(s) in all the PAS, EUTH and LAWER cases. Also multiple answers were possible: 'the patient themselves, the physician, a nurse, a family member, someone else.' Additionally, if the treating physician did not administer the drug(s), we asked whether or not the physician was present. On the basis of the answers to these questions, we differentiated between cases in which a nurse and a physician administered the drug(s) together, those in which a nurse administered the drug(s) in the presence of a physician, and those in which a nurse administered the drug(s) without attendance of a physician. In the latter cases, we made a further distinction between cases in which a physician reported that the decision had been discussed in advance with the administering nurse and cases in which there was no such discussion.

### Ethical considerations

The study was approved by the Ethics Committee of the University Hospital of the Vrije Universiteit Brussel (VUB), Belgium. Along with the questionnaire, we sent an anonymous patient file with some demographic data allowing the physicians to identify the patient. A complex mailing procedure, approved by the Belgian National Disciplinary Board of Physicians and supervised by a legal attorney, was followed to ensure the anonymity of both physician and patient, and to increase the response rate (Verstraeten *et al.* 2001).

### Data analysis

The sample that responded was compared with the national annual mortality data, and corrected for response biases. Comparisons of frequency distributions were made by

Fisher's exact test (Agresi 1990). Incidence figures were extrapolated to estimates of frequencies for all deaths with 95% confidence intervals calculated by multinomial logistic regression with, as dependent variable, the incidence of (non-)administering lethal drugs by physicians alone, by nurses and physicians together and by nurses alone in EUTH and LAWER (McCullagh & Nelder 1994, Deliens *et al.* 2000).

## Findings

The majority of nurses work in an institutional context and, because of the significant differences in characteristics between patients who died at home and in an institution, we present the results for deaths at home separately from those for in a hospital or nursing home. Results for physician-assisted suicide are not presented in this paper because these were limited to three observed cases.

### Characteristics of deaths

The characteristics of all studied deaths have been summarized in Table 1. Most deaths in Flanders occurred in institutions. The profile of 'institutional deaths' was substantially different from that of 'home deaths'. The majority of these 'institutional deaths' involved women, while the majority of 'home deaths' involved men. The inpatients were less educated and had fewer cancers, but were older and more often too ill to participate in decision-making at the moment of the ELD than patients who died at home. Almost all patients who died at home were treated by general practitioners (GPs), while most who died in an institution were treated by specialist medical officers.

### Consultation of nurses in the decision-making process

Table 2 reveals that GPs reported having consulted others in advance in three-quarters of the at-home ELD cases. They consulted a health care worker (with or without a family member) in 43% of cases, and in 31% they consulted a family member but no health care worker. Physicians in institutions reported consultations in 85% of all ELDs: usually a health care worker (78%) was involved and rarely only a family member (6%). The consulted health care worker was more likely to be a nurse in institutional cases than in at-home cases (52% vs. 21%). The consultation of a nurse by the treating physician in an institution was the highest among EUTH-cases (83%) and LAWER-cases (55%), followed by NTD-cases (51%) and APS-cases (51%). At home, we found the opposite: nurses were most often

**Table 1** Characteristics of deaths studied (weighted figures)\*

Patient characteristics <sup>†</sup>	Percentage of deaths studied		
	All deaths ( <i>n</i> = 1925)	At home ( <i>n</i> = 446) <sup>‡</sup>	In an institution ( <i>n</i> = 1406) <sup>‡</sup>
Age (years)			
1–64	18.5	23.1	14.9
> 64	81.5	76.9	85.1
Sex			
Male	49.6	59.4	45.6
Female	50.4	40.6	54.4
Education level			
Primary school	48.8	41.1	52.1
High school or college	31.5	37.8	28.8
Unknown <sup>§</sup>	19.7	21.1	19.1
Cause of death			
Cancer	27.5	37.8	24.3
Cardiovascular disease	28.7	32.9	28.0
Disease of nervous system	11.4	6.0	13.6
Other	32.4	23.3	34.1
Marital status			
Single	11.5	9.6	11.0
Widowed or divorced	45.3	33.9	50.0
Married	43.1	56.5	39.0
Competence to discuss with <sup>¶</sup>	( <i>n</i> = 738)	( <i>n</i> = 154)	( <i>n</i> = 568)
Competent	24.8	50.0	18.1
Not competent	53.1	28.6	59.3
Unknown <sup>§</sup>	22.1	21.4	22.5
Patient treated by			
General practitioner	42.5	91.3	26.9
Specialist	57.5	8.7	73.1

\*All figures adjusted to patient/mortality characteristics of all deaths in Flanders, 1998.

<sup>†</sup>Difference in distribution between characteristics of deaths at home and deaths in institution are significant (<0.001) for all characteristics, using Fisher's exact test and statistical package StatXact, v3.0.

<sup>‡</sup>Seventy-four deaths occurred not at home, neither in an institution. Institution: hospital or nursing home.

<sup>§</sup>Not included in Fisher's exact test.

<sup>¶</sup>Only known for cases where the physician reported an end-of-life decision.

consulted in APS-cases (23%), followed by NTD-cases (22%), EUTH-cases (20%) and LAWER-cases (13%). In EUTH- and LAWER-cases, physicians consulted nurses four times more frequently in an institution than at home.

### Involvement of nurses in administration of lethal drug(s)

In the main study of 1998, we found that 1.1% (estimated at approximately 600 deaths yearly) of all deaths in Flanders, Belgium was because of EUTH (Deliens *et al.* 2000). Table 3 below shows that nurses aided physicians in administering

**Table 2** Involvement of nurses, other health care workers and family members in the decision-making process

Percentage of cases* in which the physician discussed the decision with:	A nurse, with/without other health care worker or family	Health care worker, but no nurse with/without family	Family, but no health care worker	Nobody
<b>EUTH</b>				
Home ( <i>n</i> = 12)	20.0	50.0	20.0	10.0
Institution ( <i>n</i> = 10)	83.3	8.3	8.3	–
<i>P</i> -value <sup>†</sup>	0.0083	0.0557	0.5714	0.4545
<b>LAWER</b>				
Home ( <i>n</i> = 20)	12.5	18.8	37.5	31.3
Institution ( <i>n</i> = 37)	54.7	26.2	4.8	14.3
<i>P</i> -value	0.0065	0.7360	0.0039	0.1557
<b>APS</b>				
Home ( <i>n</i> = 99)	23.4	16.9	28.6	31.2
Institution ( <i>n</i> = 223)	50.8	23.2	7.1	18.9
<i>P</i> -value	< 0.001	0.2720	< 0.001	0.0273
<b>NTD</b>				
Home ( <i>n</i> = 63)	22.0	26.0	34.0	18.0
Institution ( <i>n</i> = 237)	51.4	29.5	5.7	13.4
<i>P</i> -value	< 0.001	0.7341	< 0.001	0.3810
<b>All ELDs</b>				
Home ( <i>n</i> = 194)	21.4	21.9	31.0	25.8
Institution ( <i>n</i> = 507)	52.0	25.8	6.3	15.6
<i>P</i> -value	< 0.001	0.3476	< 0.001	0.0045

\*The percentages are weighted row percentages, adjusted to patient/mortality characteristics of all 56 354 deaths in Flanders, 1998.

<sup>†</sup>Difference in distribution between deaths at home and deaths in institution, using Fisher's exact test and statistical package StatXact, v3.0.

EUTH, euthanasia; LAWER, life ending without the patient's explicit request; APS, alleviation of pain and symptoms; NTD, non-treatment decisions; ELD, end-of-life decisions.

**Table 3** Administration of lethal drugs by nurses in EUTH\* and LAWER<sup>†</sup>

Percentage of cases in which <sup>‡</sup>	EUTH		LAWER <sup>§</sup>	
	Home ( <i>n</i> = 12)	Institution <sup>¶</sup> ( <i>n</i> = 10)	Home ( <i>n</i> = 20)	Institution <sup>¶</sup> ( <i>n</i> = 37)
A nurse administered the lethal drug(s) together with the physician	17.2	–	21.0	17.9
A nurse administered the lethal drug(s), in attendance of physician	–	13.6	–	21.7
A nurse administered the lethal drug(s), without attendance of the physician, but after a previous discussion with the physician	–	45.2**	–	31.0
A nurse administered the lethal drug(s), without attendance of the physician, and without a previous discussion with the physician	–	–	5.2	12.1
Total involvement of nurses in administration of lethal drug(s)	17.2	58.8	25.2	82.7

\*The use of lethal drugs by a health care worker, with the explicit intention of ending the patient's life on the patient's explicit request.

<sup>†</sup>The use of lethal drugs by a health care worker, with the explicit intention of ending the patient's life without the patient's explicit request as too ill to do so.

<sup>‡</sup>Weighted percentages, adjusted to patient/mortality characteristics of all deaths in Flanders, 1998.

<sup>§</sup>Place of death was unknown for three LAWER-cases.

<sup>¶</sup>Institution: hospital or nursing home.

\*\*In all these cases the nurse administered the lethal drug(s) in the context of palliative team.

lethal drugs in 17% of the EUTH-deaths at home. For EUTH in an institution, nurses administered lethal drugs themselves in more than half of the cases studied: in 14% the physician

was at the bedside while the nurse administered the drugs, and in 45% the nurse gave the drugs within the context of a palliative care team, but without the attendance of a

physician. In all the latter cases, the physician discussed the decision with the nurse beforehand. Our main study in 1998 revealed that, compared with EUTH, medical LAWER because they were too ill to do so, occurred three times more frequently in Flanders. Table 3 shows that nurses were involved in administering the lethal drugs in a quarter of all the LAWER-cases at home, but in 83% of these cases in an institution. At home, nurses mainly aided the physicians in administering these drugs. In institutions, nurses primarily administered these drugs themselves: in 22% of cases, the physician was present, while in 43% the physician was absent. In three-quarters of the latter cases, physicians reported to have previously discussed the decision with the nurse.

### Administration of lethal drug(s): incidence figures and estimates

Table 4 shows that nurses were involved in administering lethal drugs in 2.54% of all deaths in Flanders. In 1.87% of all deaths, nurses administered the lethal drugs themselves, while in 1.77% the physician administered them alone, and in 0.67% nurses and physicians administered together. Nurses performed EUTH themselves in 0.36% of all deaths, or 200 cases a year. In 150 of these cases, the nurses acted without the attendance of a physician. The LAWER was performed by nurses in 1.51% of all deaths, which is about 850 cases/year. In about 600 of these cases, the nurses acted without the physician. In other words, in approximately 1000 cases/year, nurses administered lethal drugs to the patient; in 750 of these cases, they acted without a physician at the patient's bedside at the moment they administered the drugs.

### Discussion

Based on a robust nationwide death certificate study of medical end-of-life decisions, this study provides, for the first time in Belgium, reliable information about the active involvement of nurses in physician-assisted dying.

The estimation of nurse participation in ELDs, based on a representative sample of deaths, is unique worldwide and suitable for gathering reliable information about hidden practices. In general, we found that the consultation of nurses by physicians before performing an ELD was rather limited in Flanders, Belgium. For ELDs at home, this can probably be explained by the characteristic of the work setting. Not all patients who died at home received nursing care and, because of the strict working schedules of nurses, this homecare is largely limited to physical care for few minutes a day. Furthermore, the readiness of family mem-

bers to provide informal homecare might increase when their terminally ill relative moves into the last phase of life. Finally, Belgian GPs often have a long-standing and confidential relationship with their patients and usually work alone. It is much more difficult to explain why physicians did not previously consult a nurse in half of the ELD cases in an institutional context. Nurses represent the largest group of health care professionals in most institutions in Belgium (Van Tielens & Peys 2001). They care for patients 24 hours a day and have a close collaboration with physicians in a multidisciplinary team being key figures when it comes to informing physicians about patients' health status and attitudes towards possible ELDs (van der Arend 1998).

Nurse involvement in the administration of lethal drugs in ELDs is especially striking. Home nurses did not administer lethal drugs frequently; however, they did so together with the GP in one out of five lethal drugs cases. In institutions, nurses administered the drugs in more than half of the EUTH cases and even in two-thirds of the cases where lethal drugs were administered without the patient's explicit request because they were too ill to do so (LAWER), a practice considered ethically and legally even more problematic. It is difficult to derive explanations for these findings from our study, but some hypotheses may be proposed. First, the administration of lethal drugs by nurses in the presence of the treating physician (EUTH at home 17%, EUTH in institution 14%, LAWER at home 21% and LAWER in institution 40%) may be interpreted as a joint action in which the physician calls on the nurse's technical experience. Secondly, in cases in which the physician was absent but had already held a discussion with the nurse about administering drugs (EUTH in institution 45% and LAWER in institution 31%), the physician may have delegated the task to the nurse. In an institutional context, it is very common for specialists to delegate the administration of drugs to nurses. In almost all of these delegated cases, the administered drugs were opioids. The EUTH-cases, moreover, were performed in a palliative care team context, where the administration of morphine is a daily task of nurses. The LAWER-cases mostly concerned cancer patients who were too ill to be involved in decision-making at the very end of life (Deliens *et al.* 2000). Most of these patients needed large doses of painkilling drugs such as morphine and complex nursing care. The decision to administer life-ending drugs in LAWER can probably be seen as increasing the painkilling drugs *in extremis*, as the only possibility to put an end to an intolerable, irreversible and hopeless situation for a patient, with whom communication about life-ending has never been possible or has been postponed for too long.

**Table 4** Administration of lethal drugs in EUTH\* and LAWER†: incidence figures and annual estimates

	EUTH		LAWER	
	Incidence % of all deaths ( $n = 1925$ ) <sup>‡</sup>	Annual estimates ( $n = 56\ 354$ )	Incidence % of all deaths ( $n = 1925$ ) <sup>‡</sup>	Annual estimates ( $n = 56\ 354$ )
The <i>physician</i> administered the lethal drug(s)	0.68 (0.47–0.97) <sup>§</sup>	383 (265–547)	1.09 (0.82–1.45)	614 (462–817)
A <i>nurse</i> and the physician administered the lethal drug(s) together	0.10 (0.04–0.25)	56 (23–141)	0.57 (0.39–0.84)	321 (220–473)
A nurse administered the lethal drug(s)	0.36 (0.23–0.57)	203 (130–321)	1.51 (1.21–1.87)	851 (682–1054)
Attendance of physician	0.10 (0.04–0.25)	56 (23–141)	0.47 (0.30–0.72)	265 (169–406)
No attendance of physician	0.26 (0.15–0.46)	147 (85–259)	1.04 (0.78–1.39)	586 (440–783)
Total involvement of <i>nurse(s)</i> in administering lethal drug(s)	0.46 (0.34–0.65)	259 (192–366)	2.08 (1.78–2.43)	1172 (1003–1369)

\*The use of lethal drugs by a health care worker, with the explicit intention of ending the patient's life on the patient's explicit request.

†The use of lethal drugs by a health care worker, with the explicit intention of ending the patient's life without the patient's explicit request as too ill to do so.

‡Weighted incidence figures, adjusted to patient/mortality characteristics of all 56 354 deaths in Flanders, 1998.

§Asymptotic confidence intervals for multinomial distribution.

Nevertheless, even if these hypotheses are accepted, fundamental medical deontological, ethical and juridical problems remain. Even after the passage of the Belgian EUTH law and extensive public debate, administering lethal drugs remains far more controversial than either 'letting the patient die' or 'intensifying the alleviation of pain and symptoms with death as a side-effect'. Physicians' as well as nurses' associations are internally divided on this subject and an inter-professional dialogue has so far not been established. Disagreement between a physician and nurse about the acceptability of administering lethal drugs, in either direction, is a real possibility. Thus, considering the position of nurses, it is not clear whether they, while administering these drugs at the request of the physician, were always aware of the lethality of their act. Nor is it consistent with physicians' professional norms to delegate heavily consequential acts of this kind and, even more alarmingly, to do so without being present during or after the procedure. It cannot be excluded that, in some cases, nurses feel averse towards administering lethal drugs, but feel obliged to do so because of their subordinate position to the physician. Further, the lack of professional controls may lead some nurses, who are, unlike physicians, daily and most closely confronted with deteriorating patients and their family members, to feel responsible for relieving the pain by increasing dosages, even without having previously discussed this with the treating physician (LAWER at home 5% and LAWER in institutions 12%). Finally, the administration of lethal drugs, even at the request of a physician, may place nurses in a very precarious legal position because of the unconditional illegality of the act, even in the few countries where voluntary euthanasia has been de-penalized

under specific conditions (Dutch Law Gazette 2001, Belgian Law Gazette 2002). Although nurses have legally recognized rights to oppose any cooperation in the performance of euthanasia, they are mostly subordinated to physicians and therefore may be in a poor position to discuss or refuse orders and to assess whether or not the practice of the physician is according to the legal guidelines. It may also be possible that nurses were not aware of the real objective of physician's treatment.

### Study limitations

All findings in this study were based exclusively on the perceptions and reports of the physicians involved, which could have biased the results. Research indicates that people tend to over-report socially desirable behaviour; consequently, physicians might have overestimated their consultation of nurses before making an ELD (Bernard *et al.* 1984). It is difficult to know whether the results would have been more reliable if nurses had answered the questions. The unconditional prohibition by law and by nursing professional codes of the administration of lethal drugs by nurses, for example, and the vulnerable position of nurses in the health care hierarchy, might make them even more reluctant than physicians to report their participation in administering lethal drugs. On the other hand it is possible that some physicians attribute their own decisions to nurses, to protect themselves against criticism. However, there is no indication of the veracity of either of these hypotheses. Secondly, the number of questions about nurses' involvement was limited. For example, we did not investigate who initiated nurses' participation in the administration of drugs, how the final

### What is already known about this topic

- Empirical research in Belgium, Australia and the Netherlands has revealed that end-of-life decisions are prominent in medical practice.
- Nurses often cooperate closely with physicians and mostly care for terminally ill patients on a daily basis, having confidential and close relationships with patients and their next of kin.

### What this paper adds

- Nurses' participation in the decision-making process preceding end-of-life decisions is limited.
- Information about the substantial involvement of nurses in administering lethal drugs in end-of-life decisions, often in hospitals in the absence of the treating physician.
- Identification of important issues for prudent practice and legal or deontological regulations concerning end-of-life decisions.

decision was influenced by nurse consultation, reasons for not consulting a nurse, nurses' roles in reporting, decoding or assessing patients' requests, or in the preparation and aftercare of patients. Thirdly, results for some ELDs (especially EUTH) are based on a small number of cases. While reliable incidence estimations for these cases are possible because they are based on a large representative sample of death certificates and a sufficient response sample that was corrected for response bias, we still have to be careful in generalising the characteristics of such few cases.

### Conclusion

Contrary to all expectations, nurses in Belgium are largely involved in administering lethal drugs in ELDs, while their participation in the decision-making process is limited. Clearly, the restrictive professional nursing statements and unconditional legal prohibition of administration of lethal drugs to patients did not prevent nurses from participating in these acts. Following the Belgian euthanasia law, ratified in 2002, the administration of lethal drugs by nurses remains unconditionally prohibited without exception. Although communication between the physician and nurses involved in euthanasia is legally mandated, there are no formal guidelines as to the content and process of this inter-professional communication. In our opinion, this situation is inadequate to guarantee prudent practice for patients and

legal security for the health care workers involved. We need more problem-focused scientific research and an open discussion about a realistic assignment of duties between physicians and nurses about the different aspects of all kinds of ELDs, resulting in appropriate education and prudent practice guidelines to regulate this inevitable and necessary cooperation between physicians and nurses.

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