

End of life in Europe: an overview of medical practices

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Beyond the rare cases of euthanasia that hit the headlines, often concerning young people with severe injuries or disabilities, the end-of-life care of old people is a daily concern for hospital physicians and medical teams. Are decisions that could hasten death taken on a routine basis? Who takes these decisions? Pending the results of a survey under way in France, a review of the situation among some of our European neighbours sheds light on the question and rekindles the debate on the “right to die in dignity”.

The circumstances of death have changed over the last hundred years in Europe. Most people die at old or very old ages, often in a hospital or care home after a long chronic illness. A much wider range of medical treatments and palliative care has also become available. Patients, for their part, more often prefer to die peacefully rather than prolong life at all costs.

As a consequence of these changes, health professionals are increasingly faced with medical decisions that might hasten the death of their patients, and a debate on the rights of the terminally ill and on the acceptability of euthanasia and other end-of-life decisions has emerged in several countries. The Dutch and Belgian parliaments voted in favour of euthanasia in 2001 and 2002. In Switzerland, assisted suicide has been implicitly authorized for many years and in the Netherlands it was legalized by an Act of 2001 which came into force in 2002. In France, an Act passed in April 2005 and brought into force in February 2006 authorizes doctors to withhold unnecessary medical treatment or to intensify pain relief, even if this unintentionally hastens death.

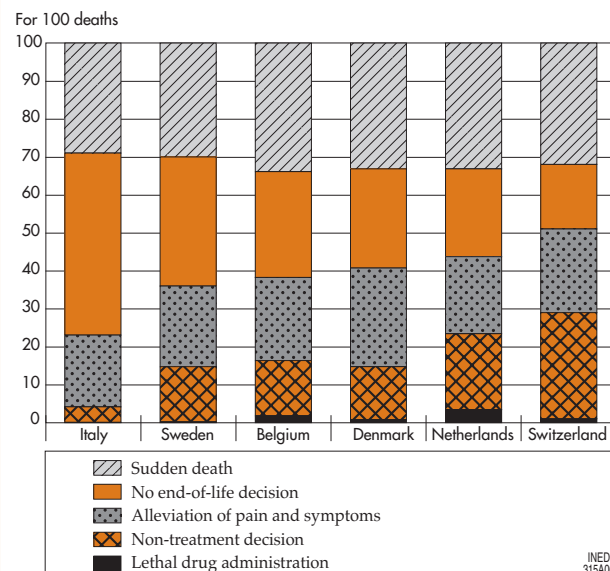
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◆ A survey of medical practice

The frequency of potentially life-shortening medical decisions was measured and compared in six European countries via the European End-of-Life Decisions survey (Eureld) completed in 2002 (see Box) [1, 2, 3, 4].

Figure 1 - Medical end-of-life decisions for 100 deaths in six European countries, 2001-2002



(J. Bilsen, J. Cohen and L. Deliens, *Population & Societies*, no. 430, INED, January 2007)

Source: [1]

The survey involved selecting a sample of deaths, identifying for each one the physician who filled in the death certificate, and sending him/her a questionnaire on the medical decisions taken preceding the end of life. The survey took place simultaneously in six European countries: Belgium, Denmark, Italy, the Netherlands, Sweden and Switzerland. A total of 20,480 deaths were studied and the physicians' response rate varied from 44% in Italy, to around 60% in Belgium, Denmark, Sweden and Switzerland, and 75% in the Netherlands.

◆ For one non-sudden death in three, a possibly life-shortening medical decision was made

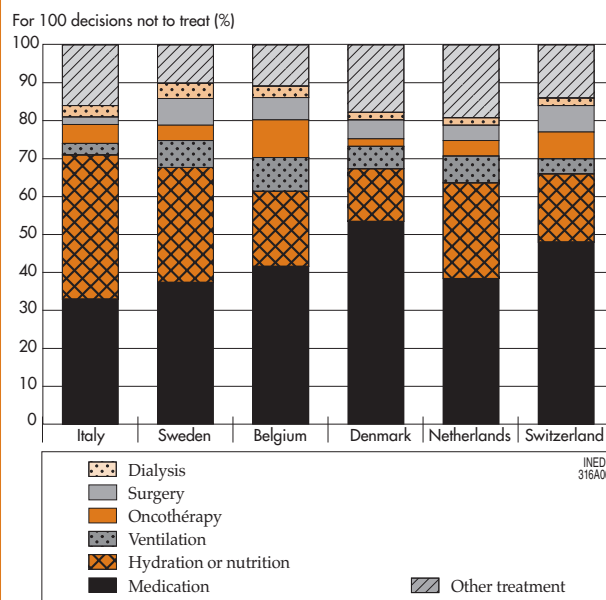
In all countries, around one-third of deaths occur suddenly and unexpectedly, excluding any end-of-life decision (Figure 1). In one-third to two-thirds of other cases, death is preceded by one or more end-of-life decisions liable to hasten the patient's death. This represents between one-quarter and a half of all deaths (23% in Italy, 51% in Switzerland). These end-of-life decisions primarily concern possibly life-shortening alleviation of pain and symptoms (19% of all deaths in Italy, 26% in Denmark). Next come decisions to withhold or withdraw treatment. These are rare in Italy (4% of deaths), but quite frequent elsewhere: around 14% of deaths in Sweden, Denmark and Belgium, 20% in the Netherlands and 28% in Switzerland. Last, physician-assisted death, with the administration of a drug explicitly intended to hasten the patient's death, is much less frequent, although it exists in all countries: according to the physicians' statements, it represents 0.1% of deaths in Italy, 1.8% in Belgium and 3.4% in the Netherlands, even though these latter two countries had not yet legalized euthanasia at the time of the survey.

◆ Pain relief or treatment withdrawal

When physicians prescribe a treatment to alleviate pain or reduce symptoms, they generally do not intend to shorten life, but they know that such a risk exists. In a minority of cases, however (from 0.4% of all deaths in Sweden to 2.9% in Belgium), it is prescribed partly with the intention of hastening the patient's death. The painkillers administered are generally opioids (from 76% of cases in Italy, to 96% in the Netherlands), most commonly strong opioids, though their type and their mode of administration vary considerably from one country to another. The doses administered in the last 24 hours of life also vary, but are generally below 300 mg of morphine oral equivalent (from 83% of cases of opioid administration in Belgium to 93% in Sweden).

The other end-of-life decisions generally involve withdrawing or withholding treatment that might

Figure 2 - Treatment withdrawn or withheld following a non-treatment decision



(J. Bilsen, J. Cohen and L. Deliens, *Population & Societies*, no. 430, INED, January 2007)

Source: [2]

otherwise prolong life. This type of decision is more frequently made with an explicit intention to hasten death (from 2% of deaths in Italy to 21% in Switzerland) than only taking into account a possible life-shortening effect (from 2% in Italy to 7% in Switzerland). Among non-treatment decisions, the withdrawal of a medication or of hydration and nutrition is most frequent (from 62% of all decisions not to treat in Belgium to 71% in Italy) (Figure 2). Non-treatment decisions are more often discussed with the patients or their family in the Netherlands (95%), in Belgium (85%) and in Switzerland (82%) than in Denmark (72%), Sweden (69%) or Italy (68%).

◆ Euthanasia is rare

Physician-assisted deaths are reported in all six countries. The physicians reported euthanasia for almost 3% of deaths in the Netherlands, but never in Sweden (Figure 3). Rare cases of physician-assisted suicide were reported in the Netherlands (0.2% of all deaths), though they are more frequent in Switzerland (0.4%), where the persons concerned are often accompanied by an association for the "right to die with dignity". Assisted suicides are very rare in Belgium and Denmark, and no cases were reported in Sweden or Italy. In each country except the Netherlands, lethal drugs are used in the majority of cases without the patient's explicit request; in Belgium, such physician-assisted deaths are five times more frequent than those following an explicit request.

Among physician-assisted deaths, from 6% (Netherlands) to 49% (Belgium) are not discussed with the patient, generally because he/she is no longer conscious when the decision is taken. The physician more frequently consults the family, though in around 20% of cases in Switzerland, Denmark and Italy, and around 30% of cases in Sweden, this is not the case. Discussions with other health professionals are less frequent in Switzerland (63%), Denmark (68%) and Sweden (71%) than in the other countries, where they take place in at least four cases out of five.

◆ Deep sedation until death

In all countries, independently of any stated intention to hasten death, drugs such as barbiturates or benzodiazepines are used to maintain patients under deep sedation, or in a coma, until death. Continuous deep sedation is most widely practiced in Italy and Belgium, where it concerns 8.5% and 8.2% of deaths respectively (Figure 4). The lowest frequencies are recorded in Denmark (2.5%) and Sweden (3.2%). In a proportion ranging from 1.6% of deaths (Denmark) to 3.2% (Belgium), deep sedation is accompanied by withdrawal of artificial nutrition and hydration. This is sometimes referred to as “terminal sedation” as it usually leads rapidly to death. Men, cancer patients, young people and persons dying in hospital are more likely than others to be placed under continuous deep sedation.

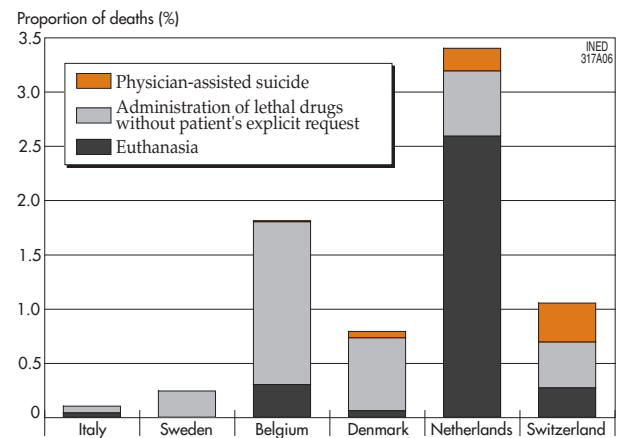
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All in all, medical end-of-life decisions which certainly or possibly hasten death are quite common in the six countries studied, where they concern one-third to two-thirds of all non-sudden deaths. With the exception of Italy, between 15 and 30% of such decisions are taken with the explicit intention of terminating the patient's life. Yet they are not always taken and executed in an appropriate manner. For example, even when the intention to hasten a patient's death is explicit, the patient or family members are not always involved in the decision-making process, and the other carers are not always consulted.

Though the administration of potentially life-shortening drugs represents only a minority of medical end-of-life decisions, the pharmacological requirements of good clinical practice are not always respected. In all countries, the directives for effective alleviation of suffering are applied incorrectly; the doses of opioids administered are often too low for example.

Last, we know little about the precautions taken when making medical end-of-life decisions. For example, the practice of continuous deep sedation may be

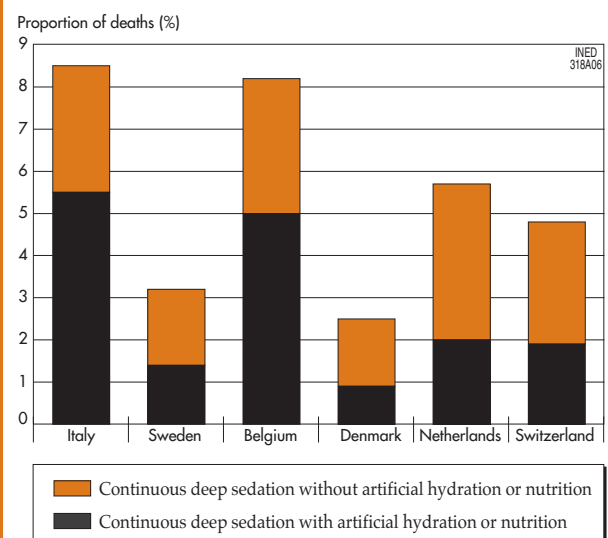
Figure 3 - Frequency of use of lethal drugs in six European countries, 2001-2002



(J. Bilsen, J. Cohen and L. Deliens, *Population & Societies*, no. 430, INED, January 2007)

Source: [1]

Figure 4 - Frequency of deep sedation until death in six European countries, 2001-2002



(J. Bilsen, J. Cohen and L. Deliens, *Population & Societies*, no. 430, INED, January 2007)

Source: [4]

viewed by some practitioners as an alternative to terminating life with lethal drugs, but without the associated legal complications, especially when nutrition and hydration have been withdrawn.

There is no doubt that practices could be improved, especially in countries without any legal framework for such decisions. To improve the quality of end-of-life care and the way it is provided, a large body of data is needed to provide a solid foundation for this difficult decision-making process. Let us hope that this type of study will be extended to other countries in the near future, notably to France, where a new law came into force in February 2006 despite inadequate knowledge of existing practices in this area.

Box

The European End-of-Life Decisions survey (Eureld)

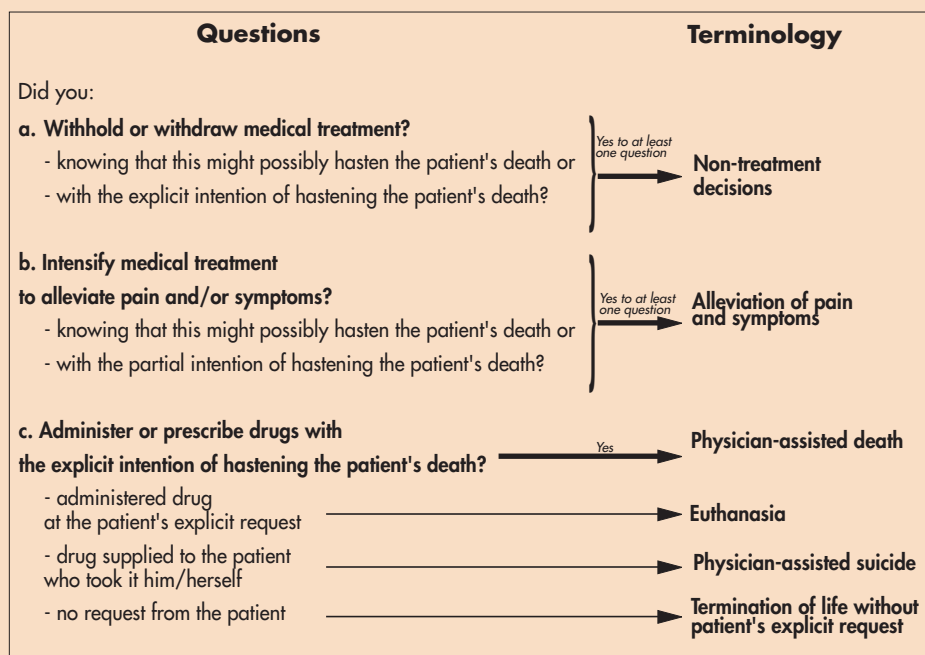
The European End-of-Life Decisions survey (Eureld) was conducted simultaneously in six European countries: Belgium (Flanders), Denmark, Italy (four regions), the Netherlands, Sweden and Switzerland (German-speaking cantons) [1,2,3,4] (1). In each country or region, random samples were constituted using the death certificates of persons who died between June 2001 and February 2002.

A questionnaire on the medical decisions preceding death were sent to the physicians who filled in the death certificates. The first questionnaire section concerned medical decisions that might possibly or would certainly hasten death (Insert). Under the classification established for the

survey, when a positive answer was given to more than one question, the most explicit decision to hasten death took precedence: a "yes" answer to question c prevails over a "yes" to question b, and a "yes" to question b prevails over a "yes" to question a. A question was also asked concerning terminal sedation: "Did you use drugs such as barbiturates or benzodiazepines to place the patient under deep sedation until death?" The second questionnaire section contained detailed questions about treatment withdrawal and medications used, where applicable.

The questionnaire avoided terms such as "euthanasia" and "physician-assisted suicide" which have diverse connotations. In all countries, a complex data collection procedure was implemented to guarantee total anonymity of both patients and physicians concerned. The data for each country were collated in a unified database so that identical codification and analysis procedures could be used. The results were weighted to be representative of all deaths during the study period in terms of sex, age, place and cause of death.

(1) The survey was coordinated by the Dutch research team (A. van der Heide, P. van der Maas, G. van der Wal and B. Philipsen).



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ABSTRACT

Physicians are increasingly faced with medical decisions liable to hasten the death of very old patients. According to the Eureld survey conducted in six European countries, medical decisions of this type occur in between a quarter and a half of deaths. In most cases, they concern potentially life-shortening pain and symptom alleviation (19% of all deaths in Italy, 26% in Denmark). Medical decisions with the explicit intention of hastening the patient's death concern between 2% (Italy) and 21% (Switzerland) of deaths. They consist in withholding or withdrawing treatment, or administering or prescribing lethal drugs. Active euthanasia by administration of lethal drugs is rare.