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End-of-life medical decisions in France

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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 elderly people is a daily concern for doctors and hospital medical teams. Are decisions that could hasten death taken on a routine basis? Who takes these decisions? Sophie Pennec, Alain Monnier, Silvia Pontone and Régis Aubry present the initial findings of a survey of end-of-life medical decisions in France.

The circumstances of death have changed over the last hundred years in France. Most deaths now occur at advanced, or very advanced ages, generally in a hospital or institution, and often preceded by a chronic illness. Persons approaching death sometimes give priority to maintaining quality of life rather than prolonging life at any cost. Palliative care is now more widely available and physicians are often obliged to make difficult end-of-life decisions. The rights of patients reaching the end of their life, the medical decisions taken at that precise moment and the question of euthanasia have become major issues of debate. Reflecting these developments, the Leonetti Act of 2005 (Box 1) entitles patients to refuse any treatment that they consider unreasonable in terms of the benefit it procures. Physicians may decide to withdraw treatments, even if this could potentially hasten death. Five years after the entry into force of the Act, we can examine medical end-of-life decisions in France using data from a recent survey on this question (La fin de vie en France, Box 2).

For more than half of non-sudden deaths, a medical decision may have hastened death

End-of-life medical decisions are generally the culmination of a complex treatment process involving a sequence of actions undertaken by the medical team. However, 17% of the deaths studied in the survey were considered by physicians to be "sudden and unexpected", excluding any possibility of medical intervention (Table).

Table: End-of-life medical decisions in France in 2010

	Number	Per 100 deaths
Decision taken knowing that the decision may hasten the death, of which:	2,252	47.7
- Withholding of life-prolonging treatment	*688*	*14.6*
- Withdrawal of life-prolonging treatmente	*199*	*4.2*
- Intensification of treatment to alleviate pain and symptoms	*1,327*	*28.1*
- Use of a drug to deliberately end life	*38*	*0.8*
Decision taken without any intention regarding death	1,097	23.2
Decision to do everything to prolong life	576	12.2
Sudden death	798	16.9
Total	**4,723**	**100**

Missing values: 168.
Source : "La fin de vie en France" survey, INED, 2010.

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Box 1

The Leonetti Act

In France, several new provisions were included in the law of 22 April 2005 concerning patients' rights and the end of life, known as the "Leonetti Act":

- it recognizes (1) the patient's right to refuse treatment that they consider to be "unreasonable" in terms of the benefit it procures and (2) the physician's right to withhold or withdraw "treatments that are futile, disproportionate or have no purpose other than to artificially prolong life";
- it reinforces the right to palliative care for all persons whose state of health so requires and recognizes, under certain conditions, that the alleviation of pain or symptoms may require drugs with the unintended side effect of hastening the patient's death.
- it reinforces the principle of "patient autonomy": a patient in an advanced or terminal stage of a serious and incurable disease, considered as competent to express his or her wishes, is entitled to refuse treatment and the physician is required to comply with the patient's wish. If the patient is not competent, the physician may withhold or withdraw treatment, but he/she must take account of any advance directive made by the patient, obtain the opinion of a trusted third party (if appointed) or, failing that, of the family, consult the medical team and obtain the informed opinion of another physician.

Box 2

The end-of-life survey in France

For the very first time, the end-of-life survey (La fin de vie en France) conducted by the National Institute for Demographic Studies (INED)(*) sheds light on the circumstances of the end of life in France. It covers a sample of 14,999 deaths of persons aged 18 and above representative of the 47,872 deaths that occurred in France in December 2009. For each death, the physician who filled in the death certificate was asked to complete a questionnaire comprising around a hundred questions on the circumstances of the patient's end of life: end-of-life decision, palliative care, implementation of provisions relative to a trusted third party, etc. The confidentiality of the responses was guaranteed by means of third parties who ensured that all information collected was totally anonymous.

A total of 14,080 questionnaires were sent to 11,828 certifying physicians, and 5,217 were returned, giving an overall response rate of 40%. This rate is around the average for national surveys of physicians in France. A total of 326 questionnaires not belonging to the sample were excluded, bringing the total number of deaths covered in the study to 4,891. Certain physicians were unable to answer the questionnaire because they did not receive it or because they had not followed the patient themselves. Others simply failed to respond. To check that these non-responses did not unduly bias the results, a telephone survey was conducted on a sample of 620 non-responding physicians. The reasons given to explain their non-response were not closely linked to the survey, and were due mainly to a lack of time. The profile of these physicians was similar to those who replied, suggesting that there was no major bias.

(1) Survey financed by the Ministry of Health (Direction générale de la Santé) and INED, and conducted by INED with the help of the Observatoire national de la fin de vie, the Centre d'épidémiologie des causes de décès (INSERM) and the Conseil national de l'Ordre des médecins.

In almost half of the deaths studied (48%), the physician reported taking a medical decision knowing that it was liable to hasten the patient's death. Most often, treatments were not administered with this intention (45%)[1] and are therefore consistent with the intent of the law. These were decisions to withhold (15%) or withdraw (3%) a life-prolonging treatment, or to intensify alleviation of pain or symptoms with opioids and/or benzodiazepines (27%).
In a very small proportion of cases (3.1%, or 148 deaths out of 4,723) an act was performed to deliberately end the person's life: decision to withhold or withdraw treatments (1.5% of deaths); intensification of treatment to alleviate pain (0.8%), or administration of drugs (0.8%) (see also Box 3 on euthanasia).
The other end-of-life medical decisions were taken either with the aim of doing everything possible to prolong life (12% of all deaths), or without any intention regarding death (23%).

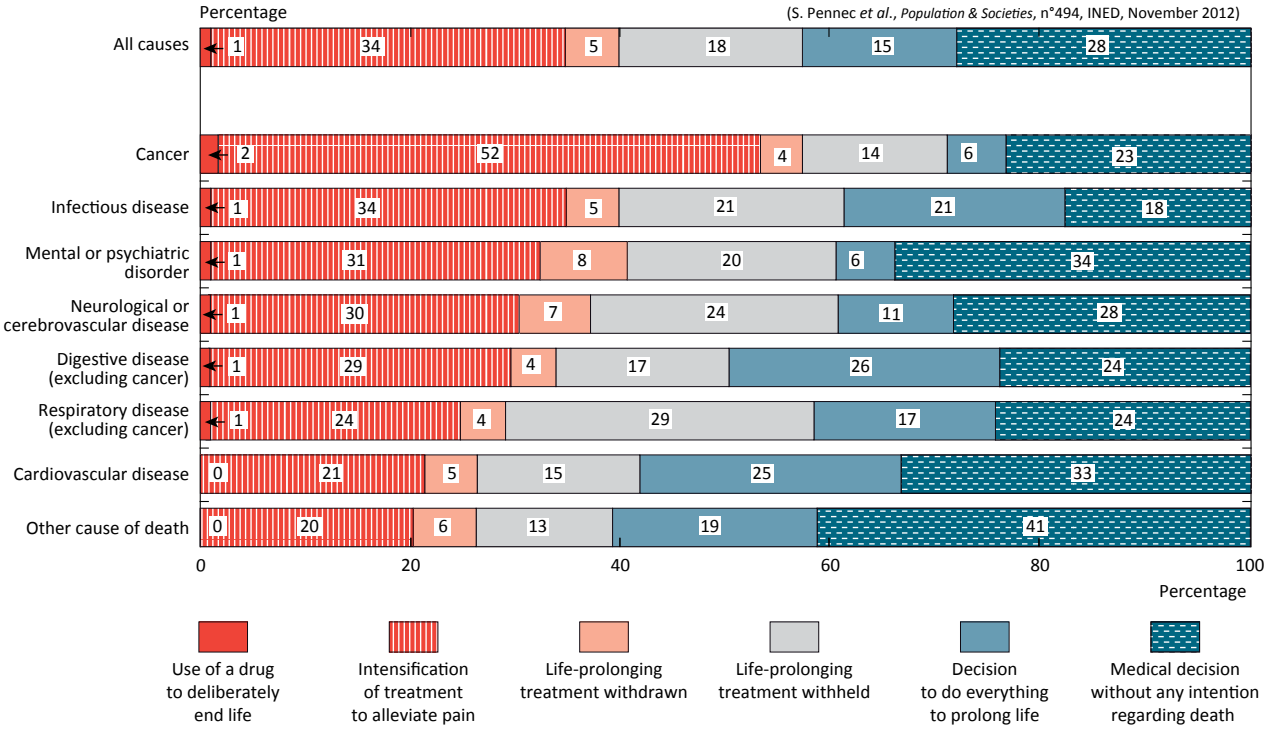
Pain relief or treatment withdrawal

For most causes of death, intensification of treatment to alleviate pain is the most frequent decision (Figure). Its frequency varies by a factor of two, however, depending on the cause: it is offered to half of cancer patients (52%) versus less than a quarter of patients with a cardiovascular disease (21%) or a respiratory disease (24%). The decision to do everything possible to prolong life is more frequent for patients with cardiovascular and digestive diseases (around 25%) than in cases of cancer or mental/ psychiatric disorders (5%). The use of a drug to deliberately hasten death is a rare practice and mainly concerns cancer patients.

Intensification of treatment to alleviate pain is much more frequent when the death occurs in hospital (38% of deaths) than when it occurs at home (22%), with deaths in a retirement home occupying an intermediate position (31%). This is probably because patients requiring intensification of treatment to alleviate pain are more frequently hospitalized. But the differences remain, even for patients with the same disease. Moreover, in retirement homes, cases where everything is done to prolong the patient's life are quite rare (below 10%), but slightly more frequent for deaths in hospital or at home (close to 16%).

(1) The figures given in these two paragraphs are not shown in the table; they are a breakdown of the figures in the table by intention or absence of intention to hasten death.

Figure: End-of-life medical decisions by cause of death



Sources : "La fin de vie en France" survey, INED, 2010.

Box 3

Euthanasia: rarely requested and seldom practiced

Euthanasia signifies "termination of person's life by a third party at his or her request" [2, 3, 4]. Decisions to end the life of persons who do not express the wish to die are not qualified as euthanasia in legal terms, including in countries where this practice has been legalized.

In this study, according to the surveyed physicians, 16% of the deceased expressed a wish at some point to hasten their death, but explicit requests for euthanasia are rare in France. They concerned 1.8% of the deaths in the sample, i.e. 44 persons out of a total of around 2,200 for whom an end-of-life medical decision was made.

The practice of euthanasia is even more rare, firstly because decisions of any kind to end a person's life are infrequent – 3.1% of deaths, i.e. 148 cases out of 4,723, with administration of a lethal drug representing just 0.8% of deaths (38 cases) – and secondly because only one-fifth of these decisions are taken at the patient's request (around one-third in the case of administration of a drug). Acts of euthanasia (ending a person's life at his/her request) represent 0.6% of total deaths in the sample, with 0.2% involving the deliberate administration of a substance to end life (11 cases). In these latter cases, fewer than 4 are defined by the physician as euthanasia, the others generally being considered as sedation to alleviate terminal distress.

The patient's age does not seem to have an effect and there are few differences by the physician's speciality. However, some specialities are an exception, because of the diseases concerned or the conditions in which the treatment is given (emergency or non-emergency in particular). Anaesthesiologists, intensivists and emergency physicians more frequently report doing everything possible to prolong life, while cancer specialists and gerontologists are more likely to intensify the alleviation of pain and/or symptoms.

A collective decision in nine cases out of ten

More than two-thirds of the persons for whom a decision to withhold or withdraw treatment is taken are judged by the physician to be not competent to take part in the decision. When patients are judged competent, these decisions are discussed with the patient in 80% of cases. The greater the likelihood that the medical decision will hasten death (intentionally or otherwise), the more frequently it is discussed with the patient. Such is the case in around 50% of decisions to withhold treatment and in 85% of cases to intensify pain relief. Slightly less than 7% of decisions to withhold or withdraw treatment are taken at the patient's explicit request, versus 19% of decisions to intensify pain relief.

The decisions are generally discussed with the medical team (63% of cases) and/or with another

Box 4

Comparison with other European countries

Compared with the results of the European End-of- Life Decision surveys (Eureld) [5, 6] and those conducted more recently in Belgium and the Netherlands, the proportion of deaths for which a decision possibly or certainly hastened death (48% in France in 2010) is around the average for Europe. It is higher than in Italy (29% in 2001) but lower than in the Netherlands (57% in 2010) and close to the levels in Switzerland (51% in 2001) and Belgium (48% in 2007). In France, the practice of intensifying alleviation of pain is comparable to that observed in Belgium in 2007, but more frequent than in most of the countries surveyed in the Eureld study in 2001. Last, decisions to withhold or withdraw treatment are equally frequent in France, Belgium and the Netherlands.

France is among the countries with a low percentage of assisted deaths (administration of drugs by the physician to deliberately end life), well below the levels in countries where euthanasia has been legalized, such as Belgium and the Netherlands [3, 4]. No medically-assisted suicides were reported in this survey, and euthanasia (at the patient's request) is rare.

physician (44%). In more than half of cases the family is included in the discussion, and in 15% of cases a trusted third party. The 38% of individuals who, in accordance with the law, had appointed a trusted third party practically always (96%) chose a member of their family. Only 8% of physicians report not discussing the decision with either colleagues or the patient's family. This percentage remains the same whether or not the patients is competent to take part in the discussion. Last, the greater the likelihood that the decision will hasten death, the more frequently the physicians report having discussed it with another physician, the medical team or the family.

According to the physicians, in around 10% of cases where treatment was withdrawn or intensified to alleviate pain, or where a drug was administered to deliberately hasten death, the decision was not discussed with the patient, even though he or she was considered competent. This is in violation of the Leonetti Act. Moreover, in 10% of cases where treatment was intensified to alleviate pain, and even in 2 of the 38 cases of drugs being administered to deliberately hasten death, the physician reported taking the decision alone.

Under the Leonetti Act, all individuals are entitled to draw up an advance directive expressing their wishes in relation to future end-of-life decisions taken on their behalf. Only 2.5% of the patients covered by the survey had drawn up such a directive, but when they existed, the physicians reported that they were an important factor in 72% of the end-of-life medical decisions taken. This clearly raises the question of people's awareness of the law and of the potentially useful role of advance directives not only for patients but also for health professionals.

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Abstract

In France, almost half of deaths (48% in 2010) are preceded by a medical decision that may hasten death. But only in 1% of cases are drugs administered to deliberately end life. The large majority of decisions taken are based on the provisions of the Leonetti Act, which enables physicians, under specific circumstances, to withhold or withdraw treatment or to administer drugs in order to alleviate pain or symptoms that may have the effect of hastening death. However, the legal provisions governing these decisions are still not always fully known or complied with: end-of-life decisions are not always discussed with the patients and medical teams, and very few patients draw up advance directives, as recommended in the Leonetti Act, to express their wishes to the physicians responsible for their care.

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