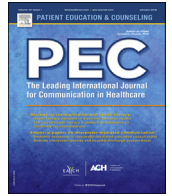




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# Do physicians discuss end-of-life decisions with family members? A mortality follow-back study

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### ABSTRACT

**Objective:** Deaths from chronic illness are often preceded by a potentially life-shortening end-of-life decision (ELD). Involving family in these ELDs may have psychosocial benefits for them and the dying person. This study aims to examine how often ELDs are discussed with relatives of the dying person and which characteristics determine their involvement in those ELDs.

**Methods:** A questionnaire survey was conducted in 2013 among physicians attending a large, stratified and representative sample of deaths (n = 6188) in Flanders.

**Results:** In 72.3% of ELDs preceding death, family of the dying person were involved. Discussion of an ELD with family members was more likely when the decision was also discussed with the dying person, the ELD was made with the explicit intention to shorten life, specialized palliative care was provided or death occurred in an ICU.

**Conclusions:** Involving family in end-of-life decision making appears to be related to the type of formal care services involved, communication with the dying person and the motives behind the decision.

**Practice implications:** Our findings suggest a need to further expand a palliative care approach with a focus on both the dying person and their family within and across a variety of health care services.

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## 1. Introduction

An increasing number of people are confronted with a relative who is dying from a chronic life-limiting disease such as cancer, dementia or cardiovascular disease [1]. These deaths are often, and increasingly, preceded by potentially life-shortening medical end-of-life decisions (ELDs) [2–9], including non-treatment decisions (withholding or withdrawing medical treatment) and increasing drug administration to relieve pain and other symptoms, or less common procedures such as physician-assisted suicide and euthanasia (defined as ‘the act, undertaken by a third party, which intentionally ends the life of a person at his or her request’ [10]). How health care providers deal with the views and concerns

of relatives of the person who is dying during the decision-making process is an important determinant of high-quality end-of-life care [11], and informing them about the consequences of a decision, thereby preparing them for the person’s death, is the least that can be expected from physicians when such a decision is being made.

While research on the incidence of end-of-life practices and the decision-making process preceding them has mostly focused on physicians and patients, there is a scarcity of empirical studies on how family members are involved in ELDs, especially in situations where the dying person has retained decision-making capacity. However, according to the World Health Organization, palliative care should aim to enhance the quality of life of both patients and their relatives who are confronted with the problems associated with life-threatening illness through the prevention and relief of physical, psychosocial and existential suffering [12]. From this perspective, it is considered as good practice to involve relatives of the people who are dying in the decision-making process, irrespective of the capacity of those dying people and without disregarding the law or denying them their right to decide for themselves. As demonstrated by a structured review about advance care planning in primary health care [13], the process

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of developing advance directives may promote conversations about ELDs between ill persons, their family and physicians at an early stage. However, according to data collected in Belgium and the Netherlands, only 8% of the persons dying from a non-sudden illness in these regions have an advance directive, with Belgians being twice less likely to have one [14].

Shared decision-making and effective and timely communication with both the dying person and their relatives have been shown to be important in providing patients and family caregivers with an optimal end-of-life experience [15]. Early and proactive communication with relatives of the dying person about the end of life can positively influence their psychosocial well-being and the bereavement process as well [16–18]. Studies show that many people also prefer their family to be involved in medical decisions made at the end of life, regardless of whether they still have decision-making capacity [19–22]. Additionally, being involved in medical decision-making may help family members to understand and accept the treatment choices of the physicians and of the person who is dying [23,24].

In 2002, Belgium adopted federal laws on patient rights, palliative care and euthanasia, making it one of the few countries – alongside the Netherlands, Luxembourg and Colombia – in which euthanasia is legal. These pieces of legislation provide a framework for increased patient autonomy in end-of-life care. Previous research on ELDs in Belgium has shown that Flemish physicians were increasingly discussing ELDs with relatives, whether the dying person possessed capacity (71% in 2001 vs. 60% in 1998) or was lacking it (77% in 2001 vs. 55% in 1998) [25]. In a comparative study between Belgium and five other European countries, only in the Netherlands was family more frequently involved in decisions regarding the end of life [26]. In 2007, however, these rates had dropped again [27]. One study notably showed that less than half of patients with lung cancer who had lost decision-making capacity had their ELD discussed by their relatives and the physician [20]. Currently, little is known about the clinical and patient characteristics that are associated with such involvement in ELDs.

Therefore, the aim of this study is to answer the following research questions: a) how often do physicians discuss ELDs with the relatives of the person who is dying in current medical practice in Flanders? b) is such involvement in ELDs associated with characteristics concerning the patient, type of ELD (i.e. patient involvement, limitation of treatment vs. active drug administration, and the intention underlying the decision) or other care characteristics?

## 2. Methods

### 2.1. Study design and study sample

This study reports findings from a postmortem questionnaire survey of physicians attending a representative sample of deaths in Flanders, asking them to report on the end-of-life decisions they made relating to those deaths. The stratified random sample was drawn by the Flemish Agency for Care and Health from death certificates of Belgian residents aged one year or older between 1 January and 30 June 2013. Firstly, all death certificates were divided into three strata based on the underlying cause of death as indicated on the death certificate. Cases were then sampled with different sampling fractions for each stratum to include not only more cases where an ELD was made, but also a sufficient amount of uncommon ELDs such as euthanasia. In the first stratum, all deaths for which euthanasia was mentioned on the death certificate were sampled. In the second stratum, one third of all cancer deaths were sampled. In the third stratum, one in six deaths resulting from any other cause were sampled. The sampling fractions reflected the

likelihood of an ELD as observed in previous surveys [28]. This procedure resulted in a sample of 6188 deaths. Each certifying physician was sent a five-page questionnaire for a maximum of five cases, with at most three reminders in cases of nonresponse. A lawyer acted as intermediary between responding physicians, researchers, and the administrative authorities for the death certificates in this mailing procedure to guarantee that completed questionnaires could never be linked to a particular decedent or physician. This lawyer also de-identified the death certificates received from the administrative authorities to the corresponding completed questionnaires received from the physicians and further anonymized the databases. After data collection, a one-page questionnaire was mailed to all non-responding physicians asking for their reasons for not participating.

### 2.2. Questionnaire

We used a slightly adapted version of a questionnaire that has been repeatedly validated in studies in the Netherlands [5], Flanders [28] and other countries [26]. It first asked whether death had been sudden and unexpected and whether the attending physician's first contact with the patient had been after death. If both questions were answered negatively (and hence end-of-life decision-making before death could not be precluded), physicians were asked whether they had withheld or withdrawn medical treatment taking into account or explicitly intending the shortening of the individual's life (non-treatment decision), had intensified the alleviation of pain and other symptoms with possible shortening of life, or had administered, supplied, or prescribed drugs with the explicit intention of hastening death (physician-assisted death). The latter act was classified as either euthanasia or physician-assisted suicide (depending respectively on whether the physician or the patient had administered the drugs) if it was done at the explicit request of the individual; without such an explicit request, the act was classified as administering life-ending drugs without explicit request. If more than one end-of-life decision was made, the one with the most explicit life-shortening intention was considered the most important, and if there was more than one act with a similar life-shortening intention, the administering of drugs was regarded as prevailing over the withholding or withdrawal of treatment. Questions about the decision-making process preceding the most important end-of-life decision and about care characteristics followed. More specifically, physicians were asked about the patient's capacity at the time of the ELD, patient and family involvement in the decision-making process, and the provision of specialized palliative care. Whether the ELD was discussed with family was determined by posing the question 'did you or another physician discuss the possible life-shortening effect of the decision with others before deciding to take the aforementioned course of action?', with the possible answer being 'yes, with the partner and/or family of the patient'.

Data on the individual's sex, age, marital status, education and underlying cause of death were available from the individually linked death certificate, while place of death was determined by a question in the questionnaire.

### 2.3. Statistical analysis

The response sample was first corrected for disproportionate stratification (by weighting each stratum to make the proportion in the response sample identical to the proportion in all deaths) and adjusted to be representative of all deaths in Flanders in the first half of 2013 in terms of age, sex and province, place, and cause of death (adjustments were needed for place of death). After this weighting procedure there were no significant differences between response sample and all deaths in any of these variables.

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