End-of-life decision-making in six European countries: descriptive study

Agnes van der Heide, Luc Deliens, Karin Faisst, Tore Nilstun, Michael Norup, Eugenio Paci, Gerrit van der Wal, Paul J van der Maas, on behalf of the EURELD consortium*

Summary

Background Empirical data about end-of-life decision-making practices are scarce. We aimed to investigate frequency and characteristics of end-of-life decision-making practices in six European countries: Belgium, Denmark, Italy, the Netherlands, Sweden, and Switzerland.

Methods In all participating countries, deaths reported to death registries were stratified for cause (apart from in Switzerland), and samples were drawn from every stratum. Reporting doctors received a mailed questionnaire about the medical decision-making that had preceded the death of the patient. The data-collection procedure precluded identification of any of the doctors or patients. All deaths arose between June, 2001, and February, 2002. We weighted data to correct for stratification and to make results representative for all deaths: results were presented as weighted percentages.

Findings The questionnaire response rate was 75% for the Netherlands, 67% for Switzerland, 62% for Denmark, 61% for Sweden, 59% for Belgium, and 44% for Italy. Total number of deaths studied was 20 480. Death happened suddenly and unexpectedly in about a third of cases in all countries. The proportion of deaths that were preceded by any end-of-life decision ranged between 23% (Italy) and 51% (Switzerland). Administration of drugs with the explicit intention of hastening death varied between countries: about 1% or less in Denmark, Italy, Sweden, and Switzerland. 1·82% in Belgium, and 3·40% in the Netherlands. Large variations were recorded in the extent to which decisions were discussed with patients, relatives, and other caregivers.

Interpretation Medical end-of-life decisions frequently precede dying in all participating countries. Patients and relatives are generally involved in decision-making in countries in which the frequency of making these decisions is high.


*Members listed at end of report

Erasmus MC, University Medical Center Rotterdam, Department of Public Health, Rotterdam, Netherlands (A van der Heide MD); Vrije Universiteit Brussel, Department of Medical Sociology and Health Sciences, Brussels, Belgium (L Deliens PhD); University of Zurich, Institute of Social and Preventive Medicine, Zurich, Switzerland (K Faisst MD); University of Lund, Department of Medical Ethics, Lund, Sweden (T Nilstun PhD); University of Copenhagen, Department of Medical Philosophy and Clinical Theory, Copenhagen, Denmark (M Norup MD); Centre for Study and Prevention of Cancer, Epidemiology Unit, Florence, Italy (E Paci MD); and Vrije Universiteit Medical Center, Department of Social Medicine and Institute for Research in Extramural Medicine, Amsterdam, Netherlands (Prof G van der Wal MD).

Correspondence to: Dr Agnes van der Heide, Department of Public Health, Erasmus MC, PO Box 1738, 3000 DR Rotterdam, Netherlands (e-mail: a.vanderheide@erasmusmc.nl)

Introduction

In most Western countries, about 1% of the population dies every year. During the past century, a shift has arisen in cause of death: acute death due to infectious disease has, to a great extent, been replaced by diseases that generally entail a more protracted dying process, such as cancer and cardiovascular disease.1 Advances in medicine have greatly improved possibilities to treat seriously ill patients and to prolong life. However, there is increasing recognition that extension of life might not always be an appropriate goal of medicine and other goals have to guide medical decision-making at the end of life, such as improvement of quality of life of patients and their families by prevention and relief of suffering.2 In some cases, hastening of death can be an accepted or—by some people—appreciated result of end-of-life care.

Medical decision-making for patients with life-threatening diseases increasingly entails a balanced consideration of medical, ethical, psychosocial, and societal aspects. These considerations and the legal background in each country could modify end-of-life decision-making practices and attitudes of doctors, patients and other people involved. Medical end-of-life decisions, in principle, include: whether to withhold or withdraw potentially life-prolonging treatment—eg, mechanical ventilation, tube-feeding, and dialysis; whether to alleviate pain or other symptoms with, for example, opioids, benzodiazepines, or barbiturates in doses large enough to hasten death as a possible or certain side effect; and whether to consider euthanasia or doctor-assisted suicide, which can be defined as the administration, prescription, or supply of drugs to end life at the patient’s explicit request. Medical end-of-life decisions can take place in any setting at which patients die—that is, in hospitals, nursing homes, hospices, and at home.

Results of comprehensive studies of medical practices in this area have thus far only been done in the Netherlands, Belgium, and Australia.3,4 Non-treatment decisions and alleviation of pain or other symptoms with large doses of opioids, in these countries, were most typical, whereas the prevalence of euthanasia, doctor-assisted suicide, and ending of life without an explicit request from the patient was much lower. The practice of non-treatment decision-making has been studied extensively in the USA, showing that, in this country, many patients die after forgoing treatment.5,6

Studies of attitudes of medical professionals towards end-of-life decision-making have been undertaken in many countries, such as Denmark, Germany, Italy, the Netherlands, Norway, Sweden, Switzerland, the UK, and the USA.4,7 However, to compare results of such surveys between countries is difficult because of differences in study designs and the ideas and definitions used. Internationally comparative studies are scarce, and have been focused on specific groups of patients, such as newborn babies or patients in intensive-care units.8,9
Therefore, to what extent practices in the area of medical end-of-life decision-making vary in Europe is unknown.

We aimed to study end-of-life decision-making in six European countries: Belgium (Flanders), Denmark, Italy (four areas), the Netherlands, Sweden, and Switzerland (German-speaking part). Legal regulations about euthanasia and assisted suicide differ in these countries: both practices are prohibited in Sweden, Denmark, and Italy. In Switzerland, assisted suicide is allowed if it is done without any self-interest, for doctors and other citizens, whereas euthanasia is forbidden. In the Netherlands, euthanasia and assisted suicide were both prohibited at the time of our study, but doctors were not prosecuted if they acted in accordance with an officially enacted notification procedure that included several guidelines for prudent practice. Euthanasia was also prohibited in Belgium at the time of our study, but a new law that allowed euthanasia under certain conditions had already been discussed; the legal status of doctor-assisted suicide was (and is) uncertain.

Our study design was identical to that of previous Dutch and Belgian studies. We assessed the number of deaths in every country that were preceded by an end-of-life decision, what the end-of-life decisions were, and some key characteristics of patients and the decision-making.

**Methods**

In every participating country or region, we obtained random samples of death certificates of people aged 1 year or older from death registers to which all deaths are reported. The sampling period varied between 3 and 6 months, but all deaths that we included arose between June, 2001, and February, 2002. In Italy, only deaths of people aged 18 years or older were included because of practical limitations attributable to decentralised registration and because studying end-of-life decision-making in minors was deemed to require even more prudence and explanation in this country. However, the number of deaths of minors is very small, and their absence in the Italian sample was not expected to greatly affect our results.

In all countries (apart from Switzerland), all deaths reported during the sampling period were stratified for the likelihood that an end-of-life decision had preceded the death involved, based on the cause of death, and deaths were assigned to one of three (Belgium, Denmark, Italy, Sweden) or five (the Netherlands) strata. Sampling fractions were higher for strata in which the cause of death involved, based on the cause of death, and deaths were assigned to. Furthermore, we made results representative for all deaths during the studied period by giving all cases an additional weight, that was calculated by dividing the sampled number and the response fraction to enhance the efficiency of the sampling stratification.

In all countries, the data-collection procedure precluded identification of any of the doctors or patients. Two follow-up mailings were used in case of non-response, but the questionnaires were only opened after all identifying information had been removed.

We combined all country-specific databases into one common file, to ensure identical coding and analysis procedures. If applicable, results were corrected for stratification by giving all cases a weight that is the reverse of the sampling fraction within the stratum they were assigned to. Furthermore, we made results representative for all deaths during the studied period by giving all cases an additional weight, that was calculated by dividing the sampled number and the response number for all cases with a specific combination of sex, age, place of dying, and cause of death (for Switzerland, only sex and age; Denmark, only sex, age, and cause of death). We used logistic regression to calculate this weight in case of small numbers.

**Key questions from the questionnaire for every death**

(a) Did you withhold or withdraw medical treatment

- while taking into account the possibility or certainty that this would hasten the patient’s death or
- with the explicit intention of hastening the patient’s death?

(b) Did you intensify the alleviation of pain and suffering

- while taking into account the possibility or certainty that this would hasten the patient’s death or
- partly with the intention of hastening the patient’s death?

(c) Was death the result of the administration, supply, or prescription of drugs with the explicit intention of hastening the patient’s death?
Table 1: Response percentages and characteristics of dead patients

Role of the funding source
Both funding sources supported the study after approval of the study design that was proposed by the investigators. They had no role in data collection, data analysis, data interpretation, or writing of the report.

Results
The total number of deaths studied was 20 480. In all countries, about half of people who died were aged 80 years or older; this proportion was highest in Italy and Sweden, whereas the proportion of people who died who were younger than age 65 years was low in these countries (table 1). Cardiovascular and malignant diseases were the most frequent causes of death in all countries. Death in hospital was most frequent in Belgium (49%) and Italy (50%).

In all countries, a third of deaths happened suddenly and unexpectedly, which precludes end-of-life decision-making (table 2). The proportion of deaths preceded by any end-of-life decision varied between 23% (Italy) and 51% (Switzerland). Doctor-assisted dying—that is, administration of drugs with the explicit intention of hastening death—was reported in all countries, but the proportion ranged from about 1% or less in Denmark, Italy, Sweden, and Switzerland, to 1·82% in Belgium and 3·40% in the Netherlands. Euthanasia was recorded to take place most frequently in the Netherlands (2·59%); no cases were reported in Sweden (table 2). Doctor-assisted suicide took place frequently in the Netherlands (0·21% of all deaths), but had a higher rate in Switzerland (0·36%). Of all doctor-assisted suicide deaths in Switzerland, 92% included the involvement of a right-to-die organisation. Doctor-assisted suicide was very rare in Belgium and Denmark, and no cases were noted in Italy and Sweden. Ending of life without the patient’s explicit request happened more frequently than euthanasia in all countries apart from the Netherlands; this type of doctor-assisted death was the only one recorded in Sweden (0·23% of all deaths).
Alleviation of pain or symptoms, while taking into account or appreciating hastening of death as a possible side-effect, happened much more frequently than doctor-assisted dying in all countries. The proportion of deaths that were preceded by such an act was lowest in Italy (19%) and highest in Denmark (26%). Frequency of non-treatment decisions—that is, decisions to withhold or withdraw potentially life-prolonging treatments—was also much higher than doctor-assisted dying in most countries, but varied more: such decisions were made in 4% of all deaths in Italy, about 14% in Belgium, Denmark, and Sweden, 20% in the Netherlands, and 28% in Switzerland.

In general, the different types of end-of-life decisions were made for patients with similar characteristics within the studied countries (table 3). Doctor-assisted dying happened frequently in patients younger than 80 years and in patients with cancer in all countries. Furthermore, it was mostly practised outside the hospital in Denmark, the Netherlands, and Switzerland. The amount of time by which life was shortened, as estimated by the doctor, was less than 1 month in most cases. Alleviation of pain or symptoms happened in all age groups, and most typically in patients with cancer. This practice took place at comparable rates in patients dying in hospital and elsewhere. Estimated shortening of life was rarely more than 1 month, and tended to be less than the estimated shortening of life in cases of doctor-assisted dying, although in a large proportion of these cases no estimation could be given. Non-treatment decisions were also made for patients in all age groups, but most frequently for those aged 80 or older. Furthermore, these decisions are not associated with specific causes or places of death. Non-treatment decisions were estimated to have shortened life

### Table 3: Characteristics of patients according to end-of-life decisions

<table>
<thead>
<tr>
<th>Country</th>
<th>Belgium</th>
<th>Denmark</th>
<th>Italy</th>
<th>Netherlands</th>
<th>Sweden</th>
<th>Switzerland</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Number of cases studied</strong></td>
<td>1351</td>
<td>1355</td>
<td>814</td>
<td>2763</td>
<td>1327</td>
<td>1704</td>
</tr>
<tr>
<td><strong>Discussion with patient and relatives</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient was competent</td>
<td>23</td>
<td>22</td>
<td>9</td>
<td>35</td>
<td>15</td>
<td>32</td>
</tr>
<tr>
<td>Decision was discussed with patient</td>
<td>67</td>
<td>58</td>
<td>42</td>
<td>92</td>
<td>38</td>
<td>76</td>
</tr>
<tr>
<td>Decision was not discussed but patient had ever expressed wish</td>
<td>8</td>
<td>13</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Decision was discussed with patient’s relatives</td>
<td>71</td>
<td>52</td>
<td>42</td>
<td>81</td>
<td>36</td>
<td>72</td>
</tr>
<tr>
<td>Decision was not discussed with patient nor relatives</td>
<td>20</td>
<td>34</td>
<td>52</td>
<td>5</td>
<td>53</td>
<td>13</td>
</tr>
<tr>
<td>Patient was incompetent</td>
<td>66</td>
<td>58</td>
<td>59</td>
<td>48</td>
<td>64</td>
<td>58</td>
</tr>
<tr>
<td>Decision was discussed with patient</td>
<td>15</td>
<td>8</td>
<td>6</td>
<td>19</td>
<td>6</td>
<td>16</td>
</tr>
<tr>
<td>Decision was not discussed but patient had ever expressed wish</td>
<td>13</td>
<td>16</td>
<td>7</td>
<td>15</td>
<td>8</td>
<td>18</td>
</tr>
<tr>
<td>Decision was discussed with patient’s relatives</td>
<td>77</td>
<td>52</td>
<td>39</td>
<td>85</td>
<td>39</td>
<td>69</td>
</tr>
<tr>
<td>Decision was not discussed with patient nor relatives</td>
<td>20</td>
<td>46</td>
<td>58</td>
<td>12</td>
<td>58</td>
<td>29</td>
</tr>
<tr>
<td>Unknown whether patient was competent</td>
<td>12</td>
<td>20</td>
<td>32</td>
<td>16</td>
<td>21</td>
<td>10</td>
</tr>
<tr>
<td><strong>Discussion with other caregivers</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other doctors</td>
<td>43</td>
<td>18</td>
<td>18</td>
<td>43</td>
<td>18</td>
<td>37</td>
</tr>
<tr>
<td>Nursing staff</td>
<td>57</td>
<td>38</td>
<td>12</td>
<td>36</td>
<td>30</td>
<td>50</td>
</tr>
<tr>
<td>No discussion with other caregivers</td>
<td>16</td>
<td>34</td>
<td>44</td>
<td>24</td>
<td>46</td>
<td>20</td>
</tr>
<tr>
<td>Unknown whether decision was discussed with other caregivers</td>
<td>7</td>
<td>20</td>
<td>32</td>
<td>14</td>
<td>18</td>
<td>8</td>
</tr>
</tbody>
</table>

### Table 4: Characteristics of decision-making for all types of end-of-life decisions
by more than 1 week most frequently compared with alleviation of pain or symptoms.

In all countries, end-of-life decision-making was most frequent for incompetent patients (table 4). The proportion of competent patients was high in countries in which the total number of end-of-life decisions was high—eg, the Netherlands (35%) and Switzerland (32%)—and vice versa. When patients were competent, the end-of-life decision was discussed with the patient and relatives most frequently in the Netherlands and least frequently in Italy and Sweden. For incompetent patients, the proportion with whom the decision was discussed or who had previously expressed a wish was highest (34%) in the Netherlands and Switzerland, and the decision was discussed with relatives most frequently in the Netherlands (85%) and Belgium (77%). In Italy and Sweden, more than 50% of end-of-life decisions, whether for competent or incompetent patients, were discussed with neither the patient nor with relatives (table 4).

Analysis of different types of end-of-life decisions separately showed that, in all countries, the pattern of decision-making characteristics was similar for both alleviation of symptoms with a possible life-shortening effect and non-treatment decisions. The numbers for euthanasia, doctor-assisted suicide, and ending of life without an explicit request from the patient were too small to make meaningful comparisons of decision-making characteristics. Written living-wills were available for fewer than 5% of patients in all countries apart from the Netherlands, where they were reported to be present in 13% (data available from authors).

Doctors consulted colleagues about their end-of-life decisions for about 40% of all patients in the Netherlands, Belgium, and Switzerland, and for fewer than 20% in the other countries. Nursing staff were asked most frequently in Belgium (57%) and Switzerland (50%).

**Discussion**

Our results show that medical end-of-life decisions frequently precede dying in all participating countries. In all studied countries, death comes suddenly and unexpectedly in about a third of all cases. For the remaining two-thirds of deaths, end-of-life decision-making seems to be an important issue.

During the preparatory phase of our study, much effort was put into creating situations that would enhance the credibility and validity of the study. Where possible, professional medical organisations or other authorities gave their support in introductory letters, and the study was presented in national or regional medical journals. Furthermore, very strict procedures were devised to guarantee anonymity for all participating doctors and for the dead patients so that all participants could be sure that none of the information that was provided would ever be used outside the context of the study—eg, in a judicial inquiry. Finally, the questionnaire we used was restricted to four pages and only contained specific and direct questions about the death involved. Doctors received the questionnaire at most 6 months after the death of the patient. Therefore, we believe that our study provides valid and reliable data on end-of-life decision-making in several European countries.

We cannot exclude the possibility that non-response has to some extent affected our results, especially for Italy. Whereas under-reporting of socially undesirable behaviour is a more common occurrence in medical research than over-reporting, such bias, if present, will probably result mainly in conservative estimates of the rates of end-of-life decisions. We must emphasise that our study was only done in specified regions in Belgium, Switzerland, and Italy, and we do not know if our findings can be extrapolated to the whole country in these cases.

Administration of drugs with the explicit intention of hastening death is practised everywhere. The rate is high in the Netherlands, which is mainly attributable to the high frequency of euthanasia—that is, administration of drugs to end life at the explicit request of the patient.

End-of-life decisions that are mainly a medical response to the suffering of patients (alleviation of pain and symptoms, ending of life without an explicit request from the patient) seem to be practised everywhere in modern health care, whereas the frequency of end-of-life decisions that are most strongly determined by cultural factors, such as patient’s autonomy, criteria for medical futility, or legal status (euthanasia, non-treatment decisions), varies much between countries. Especially for non-treatment decisions, this variation might also be related to differences in perceptions of when non-application of a treatment option is to be deemed a non-treatment decision.

Results of studies have shown that many medical interventions at the end of life are not appreciated by the patients involved, and that the dying process typically involves less than optimum communication between caregivers and terminally ill patients. Despite important advances in pain and symptom management at the end of life, many dying patients have pain and other physical and mental problems. Cardiopulmonary resuscitation, mechanical ventilation, and nasal-gastric feeding tubes are lifesaving for some patients, but for others they prolong dying and can result in great suffering for patients and their families. Therefore, involvement of patients and relatives in medical decision-making at the end of life is likely to result in higher frequencies of end-of-life decisions.

In conclusion, in six European countries, doctors have reported that end-of-life decision-making precedes dying for many of their patients. Variance in types of end-of-life decisions and decision-making characteristics should be further explored to enhance understanding of end-of-life care in modern medicine, in which the pursuit of a peaceful death seems to be widely recognised as an important goal, in addition to more traditional goals such as curing disease and avoiding premature death.

**Contributors**

All authors and members of the EURELD consortium contributed to design and implementation of the study, analysis of data, and writing of the report, and have seen and approved the final version.

**The EURELD consortium**

Johan Bilsen (Vrije Universiteit Brussel, Brussels, Belgium); Julie van Geluwe, Freddy Mortier (Ghent University, Ghent, Belgium); Annemarie Dencker, Anna Paldam Folker (University of Copenhagen, Copenhagen, Denmark); Riccardo Cecioni, Guido Miccinesi (Center for Study and Prevention of Cancer, Florence, Italy); Lorenzo Simonato (University of Padua, Padua, Italy); Silva Franchini (Local Health Authority, Trento, Italy); Alba Carola Finarelli (Regional Department of Health, Bologna, Italy); Johannes J M van Delden (Julius Center, University Medical Center Utrecht, Utrecht, Netherlands); Brege Onwuteaka-Philipsen (Vrije Universiteit Medical Center, Amsterdam, Netherlands); Rutik Löfmark (Länsjukhuset, Gävle, Sweden); and Georg Bossard, Susanne Fischer, Ueli Zellweger (University of Zurich, Zurich, Switzerland).

**Conflict of interest statement**

None declared.

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