

Empirical Research on End-of-Life Decisions in Medical Practice in Belgium (Flanders)¹

Abstract

Belgium is a country with no formal registration or authorization procedure for end-of-life decisions. Acts of euthanasia ('the administration of drugs with the explicit intention of ending the patient's life at the patient's request') are treated as murder under criminal law. In 1996, a study of euthanasia and other medical practices concerning the end of life was conducted in Hasselt, a city in the Flemish part of Belgium. All physicians who signed a death certificate in 1996 received an anonymous self-administered mail questionnaire. The response rate was 55% (75% among family physicians and 44% among clinical specialists).

This chapter explores the incidence of end-of-life decisions in Belgium (Flanders). Based on the corrected data obtained from the study in Hasselt, incidence estimates are presented for euthanasia and physician-assisted suicide, ending of life without the patient's explicit request, alleviation of pain and symptoms with a potential life-shortening effect, and withholding or withdrawing of a potential life-prolonging treatment. Furthermore, the circumstances of these end-of-life decisions that are relevant to legislation and to ethical acceptability are discussed. Based on our research experience in the domain of end-of-life decisions, we are of the opinion that the following topics deserve more attention in future research: assessment of the criteria used by physicians to define and establish the '(in)competence' of patients; patient-physician communication about the end of life under conditions of secrecy and prohibition (versus regulated conditions); research into the role of paramedical personnel, and, in particular, nurses; development and testing of causal models to explain why end-of-life decisions happen; the design of comparative international research.

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In Belgium, euthanasia is illegal and treated as intentionally causing death under criminal law. Belgian physicians could also be prosecuted for physician-assisted suicide, if the act is interpreted by the Prosecutor as the 'deliberate refusal to help a person in need'. Although euthanasia and probably also physician-assisted suicide are illegal under criminal law, actual prosecutions are exceptional and the potential legalization of these medical practices is the subject of increasing debate in Belgium, both in the official Advisory Committee on Bioethics and in the Federal Parliament. In Belgium the discussion focuses on euthanasia, strictly defined as 'a deliberate life-ending act performed by a physician at the patient's explicit request'.¹ In 1998, on the bases of a report issued by the Advisory Committee on Bioethics, the Senate spent about two days debating the desirability of the legalization of euthanasia. Representatives of the majority parties of the Parliament (newly formed after the general elections of June 1999) declared that a formal registration and authorization procedure for euthanasia would be put to the vote in the coming year. Yet, Belgium still has no formal registration or authorization procedure for end-of-life decisions in medical practice, and the hospitals and nursing homes have no written policy concerning euthanasia and physician-assisted suicide.

Since most of the deaths involving euthanasia or physician-assisted suicide are reported in the death certificates as deaths from natural causes, the incidence of euthanasia or Physician-assisted suicide cannot be deduced from official mortality statistics. Empirical research on end-of-life decisions in Belgium is rather scarce, and (prior to the study presented here) no study has ever investigated the number of deaths involving end-of-life decisions in medical practice. In 1997, a research project on end-of-life decisions was commissioned by the Fund for Scientific Research, to be carried out by an inter-university and inter-disciplinary group of researchers. Since then, some theoretical and empirical publications have been based on this research project.²⁻⁸ The results of the pilot study in the city of Hasselt were published in 1998.³⁻⁵ As it was the first study to generate empirical data on the incidence of euthanasia, physician-assisted suicide and other end-of-life decisions in Belgium, this pilot study attracted a great deal of attention in both the medical and the public press in Belgium. In 1998-1999 a nationwide study was conducted in Flanders (the Dutch-speaking region of Belgium, inhabited by approximately 60% of the Belgian population). The first results of this study have recently been submitted for publication in an international journal.⁷ This chapter focuses on the main results of the pilot study in the city of Hasselt.

The main objective of this study on end-of-life decisions is to estimate the incidence of euthanasia, physician-assisted suicide and other end-of-life decisions in medical practice in Hasselt. In this research project, physician-assisted death was defined as 'the administration of drugs with the explicit intention of shortening the patient's life', and can be divided into three sub-categories (Box 1).⁶ Euthanasia was defined as 'the administration of drugs with the explicit intention of shortening the patient's life, at the patient's explicit request'. Physician-assisted suicide was defined as 'the prescription or supply of drugs with the explicit intention of enabling the patient to shorten his life'. This study also addressed other medical end-of-life decisions. These involved life-terminating acts other than acts performed at the explicit

BOX 1 End-of-life decisions in medical practice studied

1. Physician-assisted death:

- a. *Euthanasia*:
the administration of drugs with the explicit intention of shortening the patient's life, at the patient's explicit request
- b. *Physician-assisted suicide*:
the prescription or supply of drugs with the explicit intention of enabling the patient to shorten his or her life
- c. *Ending of life without the patient's explicit request*:
the administration of drugs with the explicit intention of shortening the patient's life without an explicit request by the patient

2. Alleviation of pain and symptoms:

- a. *life-shortening not intended*:
alleviation of pain and symptoms with opioids in doses with a potential life shortening effect, but shortening the patient's life was not intended
- b. *life-shortening co-intended*:
alleviation of pain and symptoms with opioids in doses with a potential life shortening effect, and shortening the patient's life was co-intended

3. Non-treatment decisions:

- a. *life-shortening not intended*:
withholding or withdrawing of a potential life prolonging treatment, but shortening the patient's life was not intended
- b. *life-shortening co-intended*:
withholding or withdrawing of a potential life prolonging treatment, with the co-intention of shortening the patient's life
- c. *life-shortening explicitly intended*:
withholding or withdrawing of a potential life prolonging treatment, with the explicit intention of shortening the patient's life

request of the patient, and also the alleviation of pain and symptoms with the side effect of shortening of life (the 'double effect'), as well as non-treatment decisions. The ending of life without the patient's explicit request was defined as 'the administration of drugs with the explicit intention of shortening the patient's life without an explicit request from the patient'. Related to the life-shortening intention of the physician, 'alleviation of pain and symptoms with opioids in doses with a potential life-shortening effect' was divided in the sub-categories of 'not intended' and 'co-intended' by the physician. Related to the life-shortening intention of the physician, 'non-treatment decisions' were divided into three sub-categories: 'not intended', 'co-intended' and 'explicitly intended' by the physician. Box 1 shows a schematic representation of all end-of-life decision categories studied.

The Belgian research on end-of-life decisions, presented here, is the first replica of the studies, which have been carried out in the Netherlands.^{9,10} This is a neighboring country, with comparable language, culture and history, but with a somewhat different health care system and with a totally different legal arrangement for euthanasia and physician-assisted suicide. Therefore, comparisons are interesting and some criticisms of the Dutch official notification procedure for euthanasia can be addressed.

Methods

The research design and questionnaire used for the Belgian study on end-of-life decisions were almost identical to those used in the Dutch studies. The core of the mail questionnaires was based on the Dutch questionnaires used in 1990 and 1995 studies.^{9,10} Since the Dutch language is spoken both in Flanders and in the Netherlands, only a few questions had to be slightly rephrased in order to clarify certain subtle linguistic differences. Some questions were added, based on the preliminary results of the pilot study.^{3,4} In the Netherlands the death-certificate studies were conducted under legal protection of the participating physicians by the Public Prosecution and the Minister of Justice. In Belgium there was no such additional protection, so the feasibility of the research design and methods was therefore first tested in a pilot study in Hasselt.

The death-certificate study in the city of Hasselt

Hasselt is a city with 78 registered family physicians and 200 specialists, a population of 67,398 inhabitants and an annual mortality rate of 1.2 %. The study population in the study comprised all deaths which occurred in Hasselt in 1996 ($n = 970$). For each death certificate, the physician who signed it was identified and was sent one anonymous self-administered mail questionnaire per death (with a maximum of five per physician). Using the total design method, 489 questionnaires were distributed and 269 questionnaires were received back.¹³

Questionnaire

The questionnaire consisted of three parts. Part 1 described the different medical practices at the end of the life of a patient, divided into three basic categories: administration or supply of lethal drugs, alleviation of pain and symptoms, and non-treatment decisions (Box 1). The structure of the questionnaire made it possible to identify the last end-of-life decision that preceded the death of the patient. Respondents were also asked to describe their intention, with regard to the end-of-life decision: whether they took into account the possibility of life-shortening, whether shortening the patient's life was co-intended, and, finally, whether shortening the patient's life was explicitly intended. Part 2 made it possible to investigate the decision-making process that preceded the most recent end-of-life decision, and assessed a number of requirements for prudent practice (for instance, whether there had been a previously discussed and explicit request by the patient, an explicit request from relatives, whether the physician

had consulted colleagues). Part 3 provided some background characteristics of the physician. Upon receipt of the completed questionnaire, mortality data and patient characteristics were linked anonymously to the data from the questionnaire.

Response and weighting of the data

The response rate was 55% (n = 269). The response rates were 74.6% for the family physicians and 44.4% for the specialists. The results presented in this paper have been corrected for the over-representation of specialists in the non-response group.

Results

Incidence estimates

Based on the corrected data from the pilot study in Hasselt, the estimates of end-of-life decisions in Belgium (Flanders) were made. Table 1 presents the observed incidence of end-of-life decisions, as well as the estimates for 1996, based on all deaths registered during the year (n = 55,795).

Among all deaths studied in Hasselt, death occurred suddenly and unexpectedly in 35.1%; an end-of-life decision was possible, but did not occur in 27.6%, and death was preceded by at least one end-of-life decision in 37.3% (Table 1). Of all deaths, 4.8% resulted from physician-assistance (administration, prescription or supply of

Table 1. Euthanasia and other end-of-life decisions in medical practice in Belgium (Flanders), 1996.

| | n | %* | Estimates for whole nation, 1996 |
|--|-----|------|----------------------------------|
| Total number of deaths (studied) in Belgium (Flanders) | 269 | 100 | 55,795 |
| No end-of-life decision made | 169 | 62.7 | 34,983 |
| All sudden and unexpected deaths | 95 | 35.1 | 19,584 |
| All deaths without end-of-life decision in all non-sudden death situations | 74 | 27.6 | 15,399 |
| Physician-assisted death | 13 | 4.8 | 2678 |
| Euthanasia (incl. physician-assisted suicide) | 4 | 1.5 | 837 |
| Ending of life without the patient's explicit request | 9 | 3.3 | 1841 |
| Alleviation of pain and symptoms with a potentially life-shortening effect | 43 | 16.0 | 8927 |
| Shortening the patient's life was not intended | 18 | 6.8 | 3794 |
| Shortening the patient's life was co-intended | 25 | 9.2 | 5133 |
| Withholding or withdrawing of a potentially life-prolonging treatment | 44 | 16.5 | 9206 |
| Shortening the patient's life was not intended | 22 | 8.4 | 4687 |
| Shortening the patient's life was co-intended | 8 | 2.9 | 1618 |
| Shortening the patient's life was the explicit intention | 14 | 5.1 | 2846 |

* Percentages are based on the total number of deaths studied in the city of Hasselt (n = 269) and corrected for non-response bias.

lethal drugs), among which 1.5 % from euthanasia or physician-assisted suicide, and 3.3 % from the ending of life without the patient's explicit request.

The incidence of the alleviation of pain and symptoms with opioids in doses with a potential life-shortening effect was 16.0%. In 6.8% of all cases the possibility of shortening the patient's life was taken into account, but was not intended. In 9.2% of all cases shortening the patient's life was co-intended (Table 1). Non-treatment decisions occurred in 16.5% of all deaths; in 8.4% of cases the possibility of shortening the patient's life was taken into account, but was not intended; in 2.9 % of cases shortening the patient's life was co-intended; in 5.1 % of cases shortening the patient's life was the explicit intention.

Circumstances relevant to legality and to ethical acceptability

In Table 2 the intentions are related to the different types of end-of-life decisions. When an end-of-life decision was made (n = 101), in 40.6% of the cases the physicians were merely aware of the probable life-shortening effects of their acts. In 32.7% of the cases, the intention to shorten the patient's life was present, together with other considerations (alleviation of pain, treatment of anxiety or respiratory problems, et cetera). In 26.8% of the cases, ending the patient's life was the explicit objective of the end-of-life decision. Thus, in approximately 60% of the cases there was an intention to hasten the patient's death.

Table 2. End-of-life decisions and the physician's intention to shorten the patient's life (n = 269).

| | n | % | % of all deaths* |
|--|------|------|------------------|
| KNOWING that the end of life might be hastened, of which: | 41 | 40.6 | 15.2 |
| Withholding or withdrawing of a potentially life-prolonging treatment | 23 | 18 | 22.8 |
| Alleviation of pain and symptoms with a potentially life shortening effect | 17.8 | 8.5 | 6.7 |
| Life-shortening was CO-INTENDED, of which: | 33 | 32.7 | 12.3 |
| Withholding or withdrawing of a potentially life-prolonging treatment | 8 | 25 | 7.9 |
| Alleviation of pain and symptoms with a potentially life- shortening effect | 24.7 | 3.0 | 9.3 |
| Life- shortening was PRIMARILY INTENDED, of which: | 27 | 26.7 | 10.0 |
| Withholding or withdrawing of a potential life prolonging treatment | 14 | 13 | 13.9 |
| Physician-assisted death | 12.9 | 5.2 | 4.8 |
| TOTAL | 101 | 100 | 37.3 |

Chi²: p < 0.001 for end-of-life decision, that is, withholding or withdrawing of treatment or the administration of drugs, versus intention, that is, knowing that the end of life might be hastened, life-shortening was co-intended, or life-shortening was primarily intended.

* Percentages are based on the total number of deaths studied in the city of Hasselt (n = 269) and corrected for non-response bias.

In 71.3% of the cases in which an end-of-life decision was made ($n = 96$, 5 missing) the physician had neither informed the patient about the intended act, nor discussed it with the patient beforehand. The explicit consent of the patient was obtained in 8.1% of the cases. In 14.0% of cases the intended act was discussed with the patient but no explicit consent for the end-of-life decision was obtained (and perhaps not sought). There was no significant relationship between obtaining the explicit consent of the patient and the type of end-of-life decision.

The reason why the patient was not consulted ($n = 74$) in 73.5% of such cases was that, in the opinion of the physician, this was not possible. In the remaining 26.5% of the cases, the patient was not consulted or informed, although the physicians thought that it would have been possible. The reasons the physicians most frequently gave for not consulting the patient were: 'because this was clearly the best for the patient' (28.2%), 'diminished consciousness' (26.5%), 'the patient was unconscious' (18.5%), and 'the patient was suffering from dementia' (13.6%). There was no relationship between either consulting or informing the patient or not doing so and the type of end-of-life decision. In 9.8% of the cases in which the patient had not been consulted, there had been an indirect request from the patient at some time. In 15.9% of these cases there was only a request from the patient's family. In the remainder of the cases, there had not even been an indirect request. The frequency of indirect requests was not related to the type of end-of-life decision.

Finally, in about half of the cases in which an end-of-life decision had been made ($n = 101$) the physician had consulted colleagues before acting (51.0%). The percentage of end-of-life decisions preceded by the consultation of a second physician differs with the type of end-of-life decision, but the relationship was not significant (withholding or withdrawing of a potential life-prolonging treatment: 57.8%; alleviation of pain and symptoms with a potential life-shortening effect: 48.8%; physician-assisted death: 35.7%; χ^2 : $p > 0.33$).

Discussion

From our results we can conclude that end-of-life decisions are predominant in medical practice in the city of Hasselt in Belgium. The preliminary results of the nationwide study in Belgium (Flanders) seem to be similar to the results of the pilot study in Hasselt. In 37.3% of all deaths in Hasselt an end-of-life decision was involved. The strict Belgian law has not prevented physicians from performing euthanasia or making other end-of-life decisions explicitly intended to shorten a patient's life. The estimated incidence of all medical end-of-life decisions 'explicitly' intended to shorten the life of the patient was 10% of all deaths.

Prior to this study, nationwide estimates on the incidence of end-of-life decisions have been made only for the Netherlands, Australia and the United States.^{9,10,15,16} Reliable comparisons can only be made between our study and the Dutch studies

because of the shared methodology of the death certificate study (Table 3). Table 3 shows the incidence figures for the Netherlands, Australia and Belgium (Hasselt). However, the Australian data on end-of-life decisions were collected by means of a survey among physicians. Thus, in Table 3 the Australian figures are mainly presented to indicate the (possible) importance of methodological issues. The percentage of deaths preceded by an end-of-life decision in our study is very comparable with the results of the Dutch studies of 1990 and 1995. Furthermore, the estimated incidence of all end-of-life decisions where the physician intended life-shortening was also comparable with the Dutch results. Nevertheless, compared with this neighboring country, in which euthanasia and physician-assisted suicide are tolerated under certain conditions, in Belgium (Flanders) the incidence of euthanasia is lower, but the incidence of ending a patient's life without an explicit request from the patient is much higher (Table 3).

Table 3. End-of-life decisions in medical practice in the Netherlands, Australia and Belgium.

| | The Netherlands (%) | | Australia (%) | Belgium (Hasselt) (%) |
|--|------------------------|-------------------|-------------------|-----------------------------|
| End-of-life decisions | 1990* | 1995 [#] | 1996 [†] | 1996 |
| Physician-assisted death: | 2.7 | 3.3 | 5.3 | 4.8 |
| Euthanasia (incl. physician-assisted suicide) | 1.9 | 2.6 | 1.8 | 1.5 |
| Ending of life without the patient's explicit request | 0.8 | 0.7 | 3.5 | 3.3 |
| Alleviation of pain and symptoms with a potentially life-shortening effect: | 18.8 | 19.1 | 30.9 | 16.0 |
| Shortening the patient's life not intended | 15.0 | 16.3 | 24.4 | 6.8 |
| Shortening the patient's life co-intended | 3.8 | 2.8 | 6.5 | 9.2 |
| Withholding or withdrawing of a potentially life-prolonging treatment: | 17.9 | 20.2 | 28.6 | 16.5 |
| Shortening the patient's life not intended | 9.2 | 6.9 | 3.9 | 8.4 |
| Shortening the patient's life intended | 8.7 | 13.3 | 24.7 | 8.0 |
| All deaths with an end-of-life decision | 39.4 | 42.6 | 64.8 | 37.3 |

* The percentages are based on the total number of deaths in the Netherlands in 1990 (n = 128,786)⁹

[#] The percentages are based on the total number of deaths in the Netherlands in 1995 (n = 135,546)¹⁰

[†] The percentages are based on the total number of deaths in Australia between July 1994 and June 1995 (n = 125,771)¹⁵

Furthermore, comparative data on the competence of the patient, previous consultation of another physician, previous discussion of the decision with relatives or others, and the amount of time by which life was shortened, consistently support the assumption that end-of-life decisions are made with more prudence in the Netherlands than in Belgium.

Important research questions

Based on our research experience in the domain of end-of-life decisions, we think that the following topics deserve more attention in future research.

1. Assessment of the criteria that physicians apply to define and establish the 'competence' or 'incompetence' of a patient.

Some studies directly or indirectly address the question of the attitude of patients towards euthanasia or physician-assisted suicide and their competence to face end-of-life decisions.¹⁷⁻²⁰ Little is known, however, about the ways in which physicians assess 'competence'. According to the Belgian study, most of the end-of-life decisions reported by the physicians did, indeed, concern 'incompetent' patients. However, comparison of the results of the Flemish incidence study with the Dutch studies shows that Flemish physicians have both a certain reluctance to comment on the 'competence' of a patient and a certain bias toward diagnosing patients as 'incompetent'.^{7,10} In order to explain these differences, it is necessary to address the question of what standards of capacity the physicians use to define 'incompetence', how they assess patients on the basis of these standards, and how this assessment influences the end-of-life decision-making process. In other words, research on end-of-life decisions should address the 'clinical aspects of competency' more directly.

2. Patient-physician communication about the end of life under conditions of secrecy and prohibition (versus regulated conditions)

In Belgium the relative rarity of 'direct' explicit and repeated requests from the patient for life-shortening is frequently related to 'indirect' requests or previous requests made by the patient. Some physicians argue that such requests are valid. Previous verbal requests, it may be argued, closely resemble advance directives.²¹ Moreover, indirect requests have the advantage of protecting the physician from the risks of discussing possible illegal intentions. If we want to understand what is going on in exchanges in which indirect and previous requests play a role, and if we want to know whether such requests are valid, it is necessary to study more closely the dynamics of patient-physician communication under conditions of secrecy and legal prohibition. Since most of the data we have on this subject are Dutch, they mainly concern exchanges in – extremely rare – contexts of openness and may underestimate (as some would say) the ethical quality of decisions made under the veil of legal prohibition.

3. Research into the role of paramedical personnel and, in particular, nurses.

In the Belgian study on end-of-life decisions it was found that there was a great involvement of nurses in end-of-life decision-making and practice. For instance, in 35% of all cases of administration of lethal drugs, the actual administration was carried out by nurses, and a further 16% of all cases the nurses assisted the physician and/or the patient with the administration of lethal drugs. Although several studies

have addressed this issue, more comprehensive information is needed about the role of nurses as independent informers of patients and their families, as intermediaries between physicians, patients and their families, and as executors of end-of-life decisions.²²⁻²⁴

4. More causal models could be developed

Although advances have been made in the knowledge of what happens at the bed of the dying, less is known about why it happens (the determinants of end-of-life decisions). More complex causal models, integrating several levels of determinants, are needed to explain why a certain type of end-of-life decision is made.²²⁻²⁴ It may be assumed that decisions in clinical settings are dependent on higher-order arrangements. End-of-life decision-making could be considered to comprise three broad domains of provision and of interlocking regulation, namely the non-treatment area, palliative care, and active life-termination. To explain the epidemiological patterns of end-of-life decision-making, closer attention must be paid to the relationships between the domains of regulation and provision involved in end-of-life decisions. For instance, Belgium and France are increasingly focusing on the provision and regulation of palliative care, preferring to leave the domain of active life-termination uncontrolled yet prohibited, while the medical profession itself is formulating non-treatment regulation. The Netherlands is focusing on legally tolerating, yet administratively controlling active life-termination, relying on a well-established framework of non-treatment regulation, mainly formulated by the medical profession, but perhaps paying less attention to the field of palliative care. The United States, on the other hand, has mainly regulated the area of non-treatment decisions. The explanatory role of these and other higher-level arrangements should be closely examined. In developing causal models, different variables are considered to be important potential determinants of end-of-life decisions: at the personal level (for instance, the opinions and attitudes of physicians); at the organizational level (for instance, the health care organization; the access to health care; the role of professional organizations, such as medical associations, the role of ethics committees and thus of advance directives and deontological codes); at the societal level (for instance, the role of medical training and the role of public opinion). It is clear that many of these challenging aspects of research require an international comparative approach.

5. Comparative international research is needed

Because the Belgian study applied a research design and a study questionnaire which were almost identical to those used in the Dutch studies, valid comparisons can be made. This provides certain opportunities for collaborative research and for comparative analyses, based on the Dutch and the Flemish data. By doing so, some assumptions underlying public health policies can be addressed, for instance, whether a restrictive public policy approach (Belgium) which prohibits euthanasia and physician-assisted suicide, but allows other medical end-of-life decisions, may be justified on the grounds that it is more protective of the rights or interests of patients than a liberal approach (the Netherlands). Nevertheless, only a limited number of studies

have estimated the incidence of various different types of end-of-life decisions and have established the medical and ethical circumstances of these decisions.^{7,9,10,15,16} It is clear that more of these studies are needed, especially at the level of states or nations, are needed. The debates on public policy with regard to end-of-life decisions still suffer from the lack of reliable empirical evidence about the actual incidences of end-of-life decisions, as well as about the ways in which health care workers (primarily physicians and nurses) justify these decisions to themselves and to others.

Furthermore, to make valid and reliable comparisons between countries or nations, a co-ordination of the various research designs and questionnaires is needed. Due to disparate research designs, it remains unclear whether the substantial differences in the incidence of end-of-life decisions in Australia and Belgium (or the Netherlands) can be explained by real differences in medical practice in these countries or by the different research designs that have been applied ('survey among physicians' versus 'death-certificate study') (Table 3).

The importance of end-of-life research in society

The finalities of end-of-life research, whether or not epidemiological or clinical, reside in protection of terminal patients' rights or interests, improvement of the quality of life of these patients, and improvement of the quality of the medical care provided at the end of life. Changes in disease patterns in the population, in the nature of the dying process, in medical technology, and in the ways in which society handles death and dying, inevitably induced new, and forcibly experimental, ways of dealing with terminal illness. Although medical institutions and settings are the main theatre for the non-sudden dying process, the issues involved raise intricate questions about the values of life and death and the ways in which society as a whole, including health care workers, should handle them. Hence, end-of-life research is concerned with the professional, institutional, moral and legal regulation of the care provided for the dying, and also the criteria which should be applied to assess the medical, ethical and legal soundness of the guidelines which are formulated for decision-making and conduct. Clinical and epidemiological research on end-of-life decisions, in particular, has a special supportive role in this process of designing and testing both traditional and new guidelines. It focuses, unlike other disciplines, on the empirical reality of end-of-life medical practice. It may study, for instance, the incidence of different end-of-life decisions, the acceptability of the way in which a combination of drugs shortens the dying process of a patient, and the question of whether palliative care which conforms with optimal professional standards is guaranteed to make pain tolerable, et cetera.

However, it should be noted that research of this kind, although focusing on medical practice, is not limited to the establishment of 'medical' facts, but goes even further. It is partly guided by, but also generates results that may be interpreted within ethical, legal, sociological and psychological frameworks. For instance, the fact that a physician discusses a life-shortening decision with a competent patient is not only based on medical considerations, but also on 'ethical' aspects of the physician-patient

exchange. Similarly, the finding that the active termination of a patient's life is burdensome for the physician is based on a psychological fact, and the finding that the majority of the general public (or medical professionals) is in favor of a regulated legalization of euthanasia and physician-assisted suicide refers to an important sociological fact. Hence, strictly medical matters pertain to the domain of clinical and epidemiological research on end-of-life decisions, but ethical and legal reasoning, and the formulation of public policy concerning the end of life are also closely involved.

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