

Terminal Sedation and Euthanasia

A Comparison of Clinical Practices

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Background: An important issue in the debate about terminal sedation is the extent to which it differs from euthanasia. We studied clinical differences and similarities between both practices in the Netherlands.

Methods: Personal interviews were held with a nationwide stratified sample of 410 physicians (response rate, 85%) about the most recent cases in which they used terminal sedation, defined as administering drugs to keep the patient continuously in deep sedation or coma until death without giving artificial nutrition or hydration (n=211), or performed euthanasia, defined as administering a lethal drug at the request of a patient with the explicit intention to hasten death (n=123). We compared characteristics of the patients, the decision-making process, and medical care of both practices.

Results: Terminal sedation and euthanasia both mostly concerned patients with cancer. Patients receiving ter-

minal sedation were more often anxious (37%) and confused (24%) than patients receiving euthanasia (15% and 2%, respectively). Euthanasia requests were typically related to loss of dignity and a sense of suffering without improving, whereas requesting terminal sedation was more often related to severe pain. Physicians applying terminal sedation estimated that the patient's life had been shortened by more than 1 week in 27% of cases, compared with 73% in euthanasia cases.

Conclusions: Terminal sedation and euthanasia both are often applied to address severe suffering in terminally ill patients. However, terminal sedation is typically used to address severe physical and psychological suffering in dying patients, whereas perceived loss of dignity during the last phase of life is a major problem for patients requesting euthanasia.

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ONE OF THE CLASSIC THEMES of medical ethics concerns the moral acceptability of interventions to modify the dying process. The discussion about euthanasia is well known, but developments in the practice of palliative care give rise to new discussions about the ethical aspects of medical care at the end of life. One such issue is terminal sedation.

In the Netherlands, terminal sedation, defined as bringing the patient into deep sedation while forgoing artificial nutrition or hydration, was estimated to have been applied in 4% to 10% of all deaths in 2001.^{1,2} In one study,¹ 59% of all decisions to apply deep sedation were discussed with the patient. There are no specific legal rules concerning terminal sedation in the Netherlands. Euthanasia is defined as the administration of drugs with the explicit intention to end life at the patient's request, and it is legally accepted under certain conditions in Dutch law. In 2001, 2.6% of all deaths in the Netherlands were preceded by euthanasia.³

One of the characteristics of the debate about terminal sedation is that it is rather confused: people disagree about how it should be defined, the distinction between terminal sedation and euthanasia, and the conditions under which its use would be appropriate. Obviously, a discussion about terms often is also a discussion about norms: to call the sedation of a patient deep or palliative rather than terminal has implications for the moral evaluation of these actions. Terminal sedation is seen by some as euthanasia in disguise^{4,5} or as slow euthanasia,⁶ but according to others⁷⁻⁹ the 2 practices are worlds apart. The argument of the latter authors⁷⁻⁹ is that in case of terminal sedation, neither the physician nor the patient aims to cause death. They also claim that, when terminal sedation is used only in the very last phase of the illness, the cause of the patient's death is the underlying disease, not the withholding of food and fluids. Therefore, the argument goes, the patient's death is not the result of medical interventions, which should thus not be interpreted to be euthanasia. Finally,

they claim that terminal sedation is used to address clinical problems other than those addressed by euthanasia.

In this article, we describe the extent to which these claims are reflected in the empirical data that are available on medical end-of-life decisions in the Netherlands. Cases of euthanasia and terminal sedation are compared for characteristics of the physicians and patients involved, of the decision-making process, and of the clinical course that followed the decision. Insight into the extent to which these practices can be distinguished based on their clinical characteristics may contribute to the debate about whether terminal sedation resembles euthanasia.

METHODS

POPULATION

We interviewed a nationwide stratified sample of 410 physicians: 125 general practitioners, 77 nursing home physicians, and 208 clinical specialists (cardiologists; surgeons; and specialists in internal medicine, pulmonology, and neurology). The specialists involved in our study attended about 95% of all deaths in the Netherlands in 2001. The physicians representing the 5 selected clinical specialties attended 86% of all in-hospital deaths. The sample size was determined by the likelihood that these specialists had attended deaths and the likelihood that they had been involved with different types of end-of-life decisions. The respondents were selected according to the following criteria: They had to be in active practice at the time of the interview and to have actively practiced medicine within the registered specialty for the past 2 years in the same setting. All addresses were taken from the professional registries of the relevant specialties. To arrive at the desired number of 410 physicians (the number that proved to yield sufficient numbers of cases of euthanasia in previous studies^{10,11}), we sampled 482 physicians. Seventy-two physicians (15%) declined to take part in the study: 17% of clinical specialists, 18% of general practitioners, and 3% of nursing home physicians. Face-to-face interviews were conducted by experienced part-time working or recently retired physicians who were trained to use the structured questionnaires. All interviews took place between March 2002 and October 2002. We applied strict rules to ensure the anonymity of all physicians and patients studied.

MEASUREMENT INSTRUMENTS

The interview schedule addressed experiences with end-of-life decision-making processes. Terminal sedation was defined as the administration of drugs to keep the patient in deep sedation or coma until death, without giving artificial nutrition or hydration. Questions about the practice of terminal sedation concerned the physician's most recent patient to have received terminal sedation ($n=211$). Euthanasia was defined as the administration of drugs with the explicit intention of ending the patient's life at his or her explicit request. Questions about the practice of euthanasia concerned the physician's most recent patient to have received euthanasia during the period 1996 to 2002 ($n=123$). Nursing home physicians were not interviewed about their most recent case of euthanasia because it is known that only 2% to 4% of all cases of euthanasia are performed by them.² For both practices, we collected data on the patient's characteristics, such as age, sex, and main diagnosis. Type of physician was a proxy for place of death. Euthanasia is always provided at the request of the patient; for cases of terminal sedation, we asked the physicians whether they had discussed their decision to apply terminal sedation

with the patient and relatives and whether the patient had requested terminal sedation. Discussion about and requests for terminal sedation could concern deep sedation, the forgoing of artificial nutrition or hydration, or both. For both practices, the most important reasons for the request of the patient were asked. The presence of 15 symptoms, despite treatment, was evaluated on a 5-point Likert scale. Furthermore, we asked whether other treatments aimed at curing or prolonging life were available at the time of the decision-making process, the physician's intention concerning the hastening of death, which drugs were used, the time interval between administering the drugs and the death of the patient, and the estimated degree of shortening of life. Our questionnaire was largely based on questionnaires that were used in previous studies.^{10,11} Its validity was enhanced by testing it in pilot interviews.

STATISTICAL ANALYSIS

The 5 response categories of the questions about symptoms (1, "symptom not present," to 5, "symptom strongly present despite treatment") were dichotomized into "symptom present despite treatment" (response categories 4 and 5) and "symptom not present" (response categories 1, 2, and 3). All percentages were corrected for missing values, which involved less than 5% of all cases for all variables. We used t tests, χ^2 tests, and Fisher exact tests to identify differences between patients who received terminal sedation and patients who received euthanasia.

RESULTS

Of the 410 physicians interviewed, 96 reported that they had experience with both practices; 115, with terminal sedation only; and 97, with euthanasia only. The remaining 102 physicians did not have experience with either of these practices. General practitioners reported the majority of euthanasia cases (55%), whereas most cases of terminal sedation were reported by clinical specialists (49%). This means that 55% of the euthanasia cases were performed at home, whereas 49% of the terminal sedation cases occurred in a hospital.

Of the physicians' most recent cases, patients who received terminal sedation were, on average, older (mean age, 72 years) than patients who received euthanasia (mean age, 63 years) (**Table 1**). Of all patients receiving euthanasia, 88% had cancer; this percentage was 54% for patients receiving terminal sedation. In the latter group, cardiovascular diseases were also rather common (24%). In 61% of the cases, the physician had discussed the application of terminal sedation with the patient; in 34% of the cases, the patient had requested the terminal sedation; and in 27%, the physician had discussed the possibility of terminal sedation with the patient, and the patient agreed. Relatives were involved in the decision-making process in 93% of the cases. In 4% of all terminal sedation cases, there was no patient or family consent for applying deep sedation (data not shown). Euthanasia was by definition requested by the patient.

Compared with patients who received euthanasia, those who received terminal sedation were more often reported to suffer from anxiety (37% vs 16%; $P<.001$), confusion (24% vs 2%; $P<.001$), depression (17% vs 10%; $P=.06$), bedsores (14% vs 3%; $P=.002$), loss of appetite (85% vs 72%; $P=.003$), and unclear consciousness (28% vs 0%; $P<.001$) and were more likely to be inactive (88% vs 74%; $P=.001$) (**Table 2**). In contrast, patients who

Table 1. Characteristics of Patients Who Received Euthanasia or Terminal Sedation*

Characteristic	Terminal Sedation (n = 211)	Euthanasia (n = 123)	P Value†
Age, mean (SD), y	72.0 (14.0)	62.5 (14.2)	<.001
Sex			
Men	99 (47)	69 (56)	.11
Women	112 (53)	54 (44)	
Main diagnosis			
Cancer	113 (54)	108 (88)	<.001
Cardiovascular diseases	51 (24)	5 (4)	
Other	47 (23)	10 (8)	
Specialty‡			
General practitioner	53 (25)	68 (55)	<.001
Nursing home physician§	55 (26)		
Clinical specialist	103 (49)	55 (45)	
Decision			
Discussed with patient	128 (61)	123 (100)	<.001
Requested by patient	72 (34)	123 (100)	<.001
Discussed with relatives¶	196 (93)		

*Data are given as number (percentage).

†Age, *t* test; sex, χ^2 test; diagnosis, Fisher exact test; specialty, χ^2 test; and decision discussed with and decision requested by patient, χ^2 test.

‡In the Netherlands, specialty is a reliable proxy for place of death: general physicians generally attend patients dying at home, nursing home physicians attend patients dying in nursing homes, and clinical specialists generally attend patients dying in a hospital.

§Nursing home physicians were not interviewed about their most recent case of euthanasia.

||The decision to apply deep sedation or to perform euthanasia. Discussion about and requests for terminal sedation could concern either the deep sedation, the forgoing of artificial nutrition or hydration, or both.

¶Not asked in the case of euthanasia.

received euthanasia suffered more often from nausea (38% vs 23%; $P = .005$) and vomiting (22% vs 10%; $P = .004$); if only symptoms that were strongly present were considered, patients receiving terminal sedation not only experienced these symptoms but also were significantly more often reported to have pain and dyspnea and more often felt very ill than patients receiving euthanasia (data not shown). Physicians reported in 86% of the cases of terminal sedation that no other potentially curing or life-prolonging treatments were available, whereas this percentage was lower for cases of euthanasia (77%, $P = .04$).

Table 3 shows the most important reasons for patients to request either terminal sedation ($n = 72$) or euthanasia ($n = 123$), as reported by the physicians. Euthanasia requests were mostly related to patients' sense of suffering without improving (82%) and loss of dignity (63%); these percentages were lower for patients who requested terminal sedation (60% and 18%, respectively). In addition, physicians more often reported loss of independence (33%) and a feeling of immobility because of physical limitations (18%) as reasons for patients to request euthanasia compared with patients requesting terminal sedation (6% and 7%, respectively). Requests for terminal sedation were related to suffering from severe pain more often than were requests for euthanasia (57% vs 36%).

Of all cases in which physicians had administered terminal sedation, 17% involved an explicit intention of hastening death (**Table 4**). This explicit intention was related to

Table 2. Symptoms and Availability of Other Treatment Options at the Time of the Decision-Making Process*

Symptom†	Terminal Sedation (n = 211)	Euthanasia (n = 123)	P Value‡
Pain	120 (57)	63 (51)	.29
Dyspnea	90 (43)	40 (33)	.06
Coughing	53 (25)	29 (24)	.82
Nausea	49 (23)	46 (38)	.005
Vomiting	22 (10)	27 (22)	.004
Constipation	37 (18)	22 (18)	.90
Bedsore	29 (14)	4 (3)	.002
Not active	185 (88)	91 (74)	.001
Felt very ill	181 (88)	107 (87)	.82
No appetite	176 (85)	88 (72)	.003
Fatigue	150 (71)	99 (80)	.07
Unclear consciousness	59 (28)	0	<.001
Anxiety	78 (37)	20 (16)	<.001
Confusion	51 (24)	2 (2)	<.001
Depression	36 (17)	12 (10)	.06
Absence of other treatment options§	182 (86)	95 (77)	.04

*Data are given as number (percentage).

†Symptom was present despite potential treatment possibilities.

‡ P values calculated by χ^2 tests or Fisher exact tests (2-sided); absence of other treatment options, χ^2 .

§Potentially curing or life-prolonging treatments.

Table 3. Most Important Reasons* for Patients' Requests for Euthanasia or Terminal Sedation, According to Physicians

Reason	Terminal Sedation Patients Involved in Decision-Making		P Value‡
	Process (n = 72)	Euthanasia (n = 123)	
Suffering without improving	41 (60)	101 (82)	.001
Loss of dignity	12 (18)	77 (63)	<.001
Weakness and fatigue	26 (38)	53 (43)	.76
Meaningless suffering	21 (31)	46 (37)	.27
Pain	39 (57)	44 (36)	.005
Dependency	4 (6)	41 (33)	<.001
Fear of suffocating	17 (25)	30 (24)	.88
Did not want to bother relatives	6 (9)	19 (15)	.16
Sense of immobility	5 (7)	22 (18)	.04
Vomiting	10 (15)	13 (11)	.45
Being tired of living	8 (12)	7 (6)	.16
Depression	1 (1)	1 (1)	>.99
Dyspnea‡	34 (50)		
Other reasons	10 (14)	20 (16)	.66

*One or more answers possible; data are given as number (percentage).

† P values calculated by χ^2 tests and Fisher exact tests (1-sided).

‡Not asked in cases of euthanasia.

the use of sedatives in 2% of the cases, to the forgoing of artificial nutrition or hydration in 14%, and to both in 1%. Euthanasia is by definition administered with the explicit intention to hasten death. For 60% of the patients, terminal sedation was performed by administering benzodiazepines (sometimes combined with morphine) and in most remain-

Table 4. Drugs Used, Intention of the Physician, Estimated Shortening of Life, and Time Between Administering Drugs and Death*

Variable	Terminal Sedation (n = 211)	Euthanasia (n = 123)
The decision was made with the explicit intention of hastening death†‡	36 (17)	123 (100)
Drugs administered†		
Neuromuscular relaxants or barbiturates	0	108 (94)
Benzodiazepines (potentially combined with morphine but not with muscle relaxants or barbiturates)	128 (60)	3 (3)
Morphine (not combined with benzodiazepines, muscle relaxants, or barbiturates)	76 (36)	3 (3)
Other drugs	6 (3)	1 (1)
Time between administering drugs and death†		
<1 h	2 (1)	115 (94)
1-24 h	77 (37)	7 (6)
1-2 d	58 (28)	0
3-7 d	60 (29)	0
>1 wk	9 (4)	0
Estimated shortening of life†		
No shortening or <24 h	81 (40)	1 (1)
1-7 d	67 (33)	31 (26)
1-4 wk	44 (21)	60 (51)
>1 mo	13 (6)	26 (22)

*Data are given as number (percentage).

† $P < .001$, calculated by Mann-Whitney U tests.

‡Explicit intention of terminal sedation concerned: forgoing artificial nutrition or hydration (n = 29; 14% of cases); applying deep sedation (n = 4; 2%); or both (n = 3; 1%).

ing patients by administering morphine only, whereas for 94% of the patients, euthanasia was performed by administering neuromuscular relaxants or barbiturates. Of all patients who received terminal sedation, 38% died within 24 hours and 96% within 1 week after the administration of the medication, whereas most patients receiving euthanasia died within 1 hour (94%) ($P < .001$). Physicians applying terminal sedation estimated that the patient's life had been shortened by 24 hours or less in 40% of the cases, and by more than 1 week in 27%. For euthanasia, these estimates were 1% and 73%, respectively ($P < .001$).

We performed all analyses for the subgroup of respondents who had experience with both practices to determine whether differences between both practices were associated with differences in physicians' preferences for these practices. Similarly, we performed all analyses only for patients with cancer to determine whether differences between both practices are mainly attributable to differences in diagnosis. These analyses resulted in similar distributions of the data.

COMMENT

The bottom line of both practices, terminal sedation and euthanasia, obviously is a patient who suffers severely from a fatal disease. However, there are marked differences. By definition, patients receiving euthanasia were actively involved in the decision-making process. This is true of only slightly more than half of the patients receiving terminal sedation, although relatives were almost always involved. Compared with the patients receiving euthanasia, patients who were terminally sedated were, on average, older, less often suffered from cancer and more often from cardiovascular disease, and less often died at home. Terminal sedation was more often used in patients with unclear consciousness, anxiety, and con-

fusion and in the absence of other treatment options. Furthermore, patient requests for terminal sedation were more often based on pain than were requests for euthanasia, which were more often based on a sense of suffering without chance of improving and on a perceived loss of dignity and independence. The intent of the physician in cases of terminal sedation was less often to shorten life, and the shortening of life due to terminal sedation was limited. Thus, patients who are terminally sedated are generally sicker and closer to death than patients receiving euthanasia. Two findings may seem to contradict this conclusion: patients receiving euthanasia more often suffered from nausea and vomiting. However, terminal sedation is not obviously a medically appropriate answer to these symptoms. Furthermore, these symptoms may be closely connected to a sense of loss of dignity, which was a common reason for requesting euthanasia and not for requesting terminal sedation.

The finding that requests for euthanasia are often inspired by a sense of loss of dignity is described by others as well. Haverkate et al¹² found that avoiding loss of dignity is one of the most important reasons to request euthanasia. In addition, during the first year of legalized, physician-assisted suicide in Oregon, the decision to request and use a prescription for lethal medication was associated with concern about loss of autonomy or control of bodily functions, not with fear of intractable pain.¹³ Euthanasia seems to be used as a response to a crucial loss of dignity, whereas terminal sedation is not. In a study¹⁴ within the Japanese population it was shown that respondents who reject continuous deep sedation at the end of life were significantly more likely to regard dignity and preparation for death as important compared with respondents who would appreciate continuous deep sedation at the end of life.

It was found that general practitioners more often than clinical specialists performed euthanasia, whereas clinical

specialists more often performed terminal sedation than euthanasia. In the Netherlands, euthanasia is most often performed by general practitioners who typically attend patients who have cancer and die at home.² General practitioners are generally involved in long-term care for patients, with patients registered to their practice for several years or more. Most euthanasia requests and practices are performed in this context. Terminal sedation, though, is more often practiced in a hospital for patients with cancer or cardiovascular diseases. In-hospital patients may more often have severe symptoms or extreme exacerbations of conditions that require the use of terminal sedation.

Pain was an important reason for patients to request terminal sedation and, to a somewhat lesser degree, euthanasia. Although previous reports¹⁵ have mentioned that state-of-the-art palliative care should substantially control pain in 90% of cases, it is also known that many terminal patients report pain at their end of life.¹⁶

It is sometimes suggested that terminal sedation may eliminate the need for euthanasia. Our findings indicate that terminal sedation and euthanasia often address quite different clinical problems. In the case of terminal sedation, severe physical and psychological suffering prompt the physician to sedate the patient, whereas for patients requesting euthanasia, perceived loss of dignity during the last phase of life is often a major problem. This distinction does not apply to all cases of terminal sedation and euthanasia. Thus, it is likely that for some patients, terminal sedation for refractory symptoms in the dying phase may serve as a relevant alternative for euthanasia.

Our study has several limitations. First, face-to-face interviews have the disadvantages of interviewer interpretations and socially acceptable rather than fully honest answers by respondents. We attempted to eliminate these biases by carefully selecting and training the interviewers and by ensuring strict anonymity of the respondents. Second, the respondents may have had difficulties recalling the patient's characteristics; however, recall bias was probably limited because most cases involved patients who died during the preceding 2 years. Third, the terms *terminal sedation* and *euthanasia* can evoke different connotations and interpretations in respondents. We tried to avoid this problem by providing very specific definitions of the terms. In addition, not including cases of euthanasia performed by nursing home physicians may have led to some bias. However, this effect may be limited because it is known that in the Netherlands only 2% to 4% of all cases of euthanasia are performed by nursing home physicians.²

We conclude that terminal sedation and euthanasia are both applied to address severe suffering in terminally ill patients. However, terminal sedation is typically used to address severe physical and psychological symptoms in dying patients to avoid further suffering, while the patient or the patient's representatives may accept loss of control of the dying process. For patients requesting euthanasia, perceived loss of dignity during the last phase of life is a major problem. In these cases, patients may consider control of the dying process of utmost importance.

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