

# Physician Reports of Terminal Sedation without Hydration or Nutrition for Patients Nearing Death in the Netherlands

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**Background:** Terminal sedation in patients nearing death is an important issue related to end-of-life care.

**Objective:** To describe the practice of terminal sedation in the Netherlands.

**Design:** Face-to-face interviews.

**Setting:** The Netherlands.

**Participants:** Nationwide stratified sample of 482 physicians; 410 responded and 211 of these reported characteristics of their most recent terminal sedation case.

**Measurements:** Physician reports of frequency of terminal sedation (defined as the administration of drugs to keep the patient in deep sedation or coma until death, without giving artificial nutrition or hydration), characteristics of the decision-making process, drugs used, the estimated life-shortening effect, and frequency of euthanasia discussions.

**Results:** Of respondents, 52% (95% CI, 48% to 57%) had ever used terminal sedation. Of the 211 most recent cases, physicians used terminal sedation to alleviate severe pain in 51% of patients

(CI, 44% to 58%), agitation in 38% (CI, 32% to 45%), and dyspnea in 38% (CI, 32% to 45%). Physicians reported discussing with patients the decision to use deep sedation in 59% of the 211 most recent cases (CI, 52% to 66%) and the decision to forgo artificial nutrition or hydration in 34% (CI, 28% to 41%). Hastening death was partly the intention of the physician in 47% (CI, 41% to 54%) of cases and the explicit intention in 17% (CI, 13% to 22%) of cases.

**Limitations:** The generalizability of physician reports about their most recent cases to all terminal sedation cases is uncertain. In addition, the findings are subject to recall bias and may not apply to other geographic settings.

**Conclusions:** Terminal sedation precedes a substantial number of deaths in the Netherlands. In about two thirds of most recently reported cases, physicians indicated that in addition to alleviating symptoms, they intended to hasten death.

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Patients nearing death frequently have symptoms such as dyspnea, agitation, pain, and anxiety (1, 2). One of the most important goals of the medical care provided to these patients is the alleviation of these symptoms (3). If treatment with analgesic or anxiolytic agents is not effective, sedatives are sometimes used as an alternative to render patients unconscious and then oblivious to their symptoms (4, 5). Subsequently, if artificial nutrition and hydration are not given, death will follow soon.

The ethical debate about this practice focuses on the extent to which it should be considered an end-of-life decision that possibly or certainly hastens death. Previous studies have explored the differences and similarities with other end-of-life decisions, such as euthanasia and physician-assisted suicide (6-19). However, little information exists on the medical practice of deep sedation with the forgoing of artificial nutrition or hydration in patients nearing death. Estimates about the frequency of deep sedation at the end of life vary from 15% to more than 60%, depending on the settings studied and the definitions used (4, 5, 20-26). The terminology used reflects these differences in definition of the practice of deep sedation at the end of life. Although "terminal sedation" is the most commonly used term, other frequently used terms, which demonstrate the different perspectives from which this practice is viewed, are "sedation for intractable distress in the im-

minently dying," "palliative sedation therapy," "slow euthanasia," "opioid coma," or "anesthetic coma" (6, 27-30).

The present study describes the practice of terminal sedation in the Netherlands. This study was part of the evaluation of the notification procedure for physician-assisted death in the Netherlands, which was commissioned by the ministers of Health and Justice (31).

## METHODS

### Respondent Characteristics

We interviewed a nationwide sample of 410 physicians: 208 clinical specialists, 125 general practitioners, and 77 nursing home physicians. In the Netherlands, clinical specialists provide hospital care, general practitioners provide nonspecialized care outside the hospital, and nursing home physicians work in long-term care institutions mainly for elderly people. The proportions of deaths in these health care settings are approximately 35%, 42%, and 23%, respectively. The specialties involved in our study covered about 95% of all deaths in the Netherlands in 2001. The respondents were selected according to the following criteria: They were required 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, 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. Nonresponders did not differ in age from responders.

Face-to-face interviews were conducted by experienced part-time working or recently retired physicians who were trained to administer 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.

### Interview Process

The interview schedule addressed experiences with end-of-life decision making (**Appendix Figure** [Questionnaire on Terminal Sedation], available at [www.annals.org](http://www.annals.org)). 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. The respondents were first asked whether they had ever used terminal sedation and, subsequently, how often they had performed this practice in 2000 and 2001. Additional questions about the practice of terminal sedation concerned the physician's most recent patient to have received terminal sedation ( $n = 211$ ). The physicians were asked about the patient's characteristics; whether or not sedation or the forgoing of artificial nutrition or hydration had been discussed with the patient, family, or other health care professionals; the drugs used; the intention of the physician; the estimated life-shortening effect; and whether euthanasia was discussed during the decision process.

### Statistical Analysis

We calculated all estimates about the occurrence of terminal sedation in the Netherlands by weighting the estimates of individual physicians. Weighting factors were based on differences in sampling fractions and response rates for the different specialties. These sampling fractions were 125 of 7027 for general practitioners, 77 of 810 for nursing home physicians, 34 of 394 for cardiologists, 34 of 545 for neurologists, 69 of 1321 for specialists in internal medicine, 35 of 325 for pulmonologists, and 36 of 769 for surgeons. The probabilities used to determine sampling weights were 1 in 56 for general practitioners, 1 in 11 for nursing home physicians, 1 in 12 for cardiologists, 1 in 16 for neurologists, 1 in 19 for specialists in internal medicine, 1 in 9 for pulmonologists, and 1 in 21 for surgeons.

Data on the 211 most recent patients seen by physicians were not weighted. All analyses were done by using SPSS software, version 10.0 (SPSS, Inc., Chicago, Illinois).

### Role of the Funding Sources

The sponsors approved the study design but were not involved in the collection, analysis, or interpretation of the data or in the decision to submit the manuscript for publication.

### Context

Terminal sedation, the administration of sedating medications with cessation of nutrition and hydration, is an option for care of patients who are nearing death. However, little is known about physician's experience with terminal sedation.

### Contribution

Of more than 400 physicians in the Netherlands who completed a survey about end-of-life care, just over half had ever used terminal sedation. Common reasons for using terminal sedation were relief of pain, agitation, or dyspnea. Hastening death was the primary intention in only 17% of reported cases.

### Caution

Because attitudes and practices regarding terminal sedation vary geographically and culturally, it is unclear whether these results are generalizable outside of the Netherlands.

—The Editors

## RESULTS

Most of the 410 physicians interviewed (76%) were men; 51% were clinical specialists, 30% were general practitioners, and 19% were nursing home physicians (**Tables 1 and 2**). Of all physicians, a weighted percentage of 52% (95% CI, 48% to 57%) had ever practiced terminal sedation. This percentage was 55% (CI, 49% to 62%) for clinical specialists, 48% (CI, 39% to 57%) for general practitioners, and 75% (CI, 64% to 83%) for nursing home physicians. We asked all interviewed physicians to estimate the total number of times they performed terminal sedation in 2000 and 2001. These numbers were extrapolated to the total number of 140 377 deaths in 2001 by multiplying them with the weighting factor for each specialty and assuming that the numbers were similar for the 5% of deaths covered by hospital doctors from specialties other than the ones included in our study. This extrap-

**Table 1. Characteristics of Interviewed Physicians**

Variable	Physicians ( $n = 410$ ), %
<b>Sex</b>	
Male	76
Female	24
<b>Age</b>	
30–44 y	35
45–54 y	45
≥55 y	20
<b>Specialty</b>	
Clinical specialist	51
General practitioner	30
Nursing home physician	19

**Table 2. Proportion of Deaths per Specialty\***

Specialty	Deaths (n = 140 377), %
Clinical specialist	35
General practitioner	42
Nursing home physician	23

\* From Statistics Netherlands; Central Death Registry 2001 (32).

olation suggests that physicians used terminal sedation in 10.0% (CI, 9.1% to 10.8%) of all deaths in that year. Of the 10.0% of deaths preceded by terminal sedation, 5.5% (CI, 5.0% to 6.1%) were attended by clinical specialists, 2.5% (CI, 1.9% to 3.2%) by general practitioners, and 2.0% (CI, 1.7% to 2.2%) by nursing home physicians.

Of all physicians who had ever used terminal sedation, 211 provided information about their most recent cases of terminal sedation (103 clinical specialists, 53 general practitioners, and 55 nursing home physicians). Of these most recent cases, 78% (CI, 72% to 83%) involved patients 65 years of age or older and 54% (CI, 47% to 60%) involved patients who had cancer (Table 3). Clinical specialists and nursing home physicians also frequently reported practicing terminal sedation in patients with cardiovascular diseases. The most frequently mentioned reasons for using terminal sedation were the alleviation of pain (51% [CI, 44% to 58%]), agitation (38% [CI, 32% to 45%]), dyspnea (38% [CI, 32% to 45%]), and anxiety (11% [CI, 8% to 16%]).

In 59% (CI, 52% to 66%) of the most recent cases seen by physicians, the physician had discussed the sedation with the patient (Table 4); in 33% (CI, 27% to 39%) of the cases, the patient had requested deep sedation. The main reasons for not discussing deep sedation with the patient were the fact that the patient was incompetent or subcomatose (25% [CI, 20% to 31%]). The decision to forgo artificial nutrition or hydration was discussed less frequently with the patient; the respondents reported discussing this topic in 34% (CI, 28% to 41%) of their most recent cases and receiving a request from the patient to forgo artificial nutrition or hydration in 9% (CI, 6% to 13%). Next to patient incompetence (37% [CI, 31% to 44%]), another frequently mentioned reason for not discussing the decision to forgo artificial nutrition or hydration was that many physicians perceived this not as optional but rather as a given; they considered terminal sedation to preclude the concomitant use of artificial nutrition and hydration (23% [CI, 18% to 29%]) (data not shown).

The decision to use sedation was discussed with relatives of the patient in 93% (CI, 89% to 96%) of the most recent cases seen by physicians, and the decision to forgo artificial nutrition or hydration was discussed with relatives in 73% (CI, 67% to 79%) of the most recent cases. The physicians had discussed the sedation with other caregivers in 79% (CI, 73% to 84%) of cases and had discussed

forgoing artificial nutrition or hydration in 67% (CI, 60% to 73%) of cases. Clinical specialists, nursing home physicians, and general practitioners discussed the sedation with other physicians in 76% (CI, 67% to 83%), 38% (CI, 26% to 52%), and 29% (CI, 18% to 42%) of their most recent cases, respectively. Nurses were often involved in the decision making by clinical specialists and nursing home physicians. Specialists in palliative care from other institutions were rarely consulted. In 17% (CI, 12% to 22%) of the physicians' most recent cases, neither the sedation nor the forgoing of artificial nutrition or hydration was discussed with other caregivers, and in 1% (CI, 0% to 4%) of the cases, these decisions were not discussed with the patient, the relatives, or other caregivers (data not shown).

Most physicians recalled having administered benzodiazepines in their most recent cases of terminal sedation. Twenty-one percent (CI, 16% to 27%) of physicians used only these drugs; 35% (CI, 29% to 42%) combined benzodiazepines with morphine, and 4% (CI, 2% to 8%) combined benzodiazepines with another drug (Table 5). In the remaining cases, physicians mostly used morphine. No physicians used barbiturates. General practitioners and nursing home physicians reported using benzodiazepines relatively frequently, which is in contrast to the clinical specialists, who were more likely to administer morphine only.

Of all physicians, 36% (CI, 29% to 42%) reported having made their most recent decision to perform terminal sedation without the intention of hastening death. The

**Table 3. Characteristics of the Sample Consisting of Each Physician's Most Recent Case of Terminal Sedation\***

Variable	Sample Consisting of Physician's Most Recent Case (n = 211), n (%)	All Deaths in the Netherlands in 2001, %
<b>Sex</b>		
Male	99 (47)	49
Female	112 (53)	51
<b>Age†</b>		
0–64 y	46 (22)	20
65–79 y	88 (42)	35
≥80 y	76 (36)	46
<b>Main diagnosis</b>		
Cancer	113 (54)	27
Cardiovascular diseases	51 (24)	25
Pulmonary diseases	14 (7)	10
Nervous system diseases	17 (8)	11
Other	16 (8)	27
<b>Reason for deep sedation‡</b>		
Pain	108 (51)	NA
Agitation	80 (38)	NA
Dyspnea	80 (38)	NA
Anxiety	24 (11)	NA
Other	62 (29)	NA

\* NA = not available.

† In 1 case, information on age was missing.

‡ One or more answers are possible.

**Table 4. Discussion about Deep Sedation and Forgoing Artificial Nutrition or Hydration in Each Physician's Most Recent Case of Terminal Sedation, by Physician Specialty**

Topic of Discussion	Cases Seen by Clinical Specialists (n = 103), n (%)	Cases Seen by General Practitioners (n = 53), n (%)	Cases Seen by Nursing Home Physicians (n = 55), n (%)	Cases Seen by All Physicians (n = 211), n (%)
<b>Deep sedation</b>				
Discussed with patient	67 (65)	28 (53)	30 (55)	125 (59)
Requested by patient	36 (35)	19 (36)	14 (25)	69 (33)
Reason for not discussing*				
Patient was incompetent or subcomatose	27 (26)	13 (25)	13 (24)	53 (25)
Deep sedation was clearly in the best interest of the patient	4 (4)	4 (8)	6 (11)	14 (7)
Patient had dementia	2 (2)	1 (2)	12 (22)	15 (7)
Discussion would have done more harm than good	0 (0)	1 (2)	1 (2)	2 (1)
Other reason	5 (5)	5 (9)	3 (5)	13 (6)
Discussed with relatives†	94 (91)	48 (92)	53 (96)	195 (93)
Discussed with other caregivers*†	91 (88)	30 (57)	46 (84)	167 (79)
Another physician	78 (76)	15 (29)	21 (38)	114 (54)
Nurses	70 (68)	14 (27)	41 (75)	125 (60)
Specialists in palliative care from other institutions	3 (3)	5 (10)	0 (0)	8 (4)
Multidisciplinary pain management team	8 (8)	2 (4)	0 (0)	10 (5)
Other	4 (4)	6 (12)	4 (7)	14 (7)
<b>Forgoing artificial nutrition or hydration</b>				
Discussed with patient‡	33 (33)	14 (27)	23 (43)	70 (34)
Requested by patient‡	9 (9)	3 (6)	6 (11)	18 (9)
Discussed with relatives‡	68 (67)	34 (65)	49 (91)	151 (73)
Discussed with other caregivers*§	76 (75)	20 (38)	43 (80)	139 (67)
Another physician	58 (57)	10 (19)	14 (26)	82 (39)
Nurses	60 (59)	11 (21)	41 (76)	112 (54)
Specialists in palliative care from other institutions	3 (3)	1 (2)	0 (0)	4 (2)
Multidisciplinary pain management team	4 (4)	1 (2)	0 (0)	5 (2)
Other	1 (1)	4 (8)	4 (7)	9 (4)

\* One or more answers are possible.

† In 1 case, information was missing.

‡ In 4 cases, information was missing.

§ In 3 cases, information was missing.

physicians partly had the intention to hasten death in 47% (CI, 41% to 54%) of cases and had the explicit intention to hasten death in 17% (CI, 13% to 22%) of cases. This explicit intention involved only the sedation in 2% (CI, 1% to 5%) of the physicians' most recent cases, only the forgoing of artificial nutrition or hydration in 14% (CI, 10% to 19%) of cases, and both sedation and the forgoing of artificial nutrition or hydration in 1% (CI, 0% to 4%) of cases.

Of the physicians reporting a recent case, 40% (CI, 34% to 45%) estimated that the patient's life had been shortened by 24 hours or less. In 27% (CI, 21% to 33%) of the cases, life was estimated to have been shortened by more than 1 week.

Thirty-seven percent (CI, 30% to 43%) of physicians discussed the option of euthanasia with the patient during the decision-making process. The main reasons for deciding against euthanasia were as follows: The patient preferred terminal sedation (9% [CI, 5% to 14%]); the patient did not explicitly request euthanasia (8% [CI, 5% to 12%]); and the patient viewed terminal sedation as less

disturbing to the natural process of dying than euthanasia (4% [CI, 2% to 8%]).

## DISCUSSION

Terminal sedation is frequently used in end-of-life care in the Netherlands. Half of all physicians have practiced terminal sedation. Our study shows that terminal sedation preceded an estimated 10% (CI, 9% to 11%) of all deaths in the Netherlands. Another recent Dutch study with a different study design estimated the incidence of terminal sedation to be 4% of all deaths (31). These percentages are lower than the previously reported percentages of 15% to 60% (4, 5, 20–24, 26). This difference is probably explained in part by the fact that the incidences found in most other studies do not refer to all deaths in a population but rather to deaths in a selected inpatient care setting, such as a hospital or a hospice (4, 5, 20, 22–25). Another factor that may explain the higher rates of terminal sedation in other studies is our very specific definition of terminal sedation: Patients had to be deeply sedated or comatose, and



**Table 5. Drugs Used, Intention of the Physician, Estimated Shortening of Life, and Discussion about Euthanasia in Each Physician's Most Recent Case of Terminal Sedation, by Physician Specialty**

Variable	Clinical Specialists (n = 103), n (%)	General Practitioners (n = 53), n (%)	Nursing Home Physicians (n = 55), n (%)	All Physicians (n = 211), n (%)
<b>Drugs used*</b>				
Only benzodiazepines	12 (12)	14 (26)	19 (35)	45 (21)
Benzodiazepines in combination with morphine or morphine derivatives†	35 (34)	17 (32)	22 (40)	74 (35)
Benzodiazepines in combination with other drugs (excluding morphine or morphine derivatives)	2 (2)	7 (13)	0 (0)	9 (4)
Only morphine or morphine derivatives	44 (43)	10 (19)	12 (22)	66 (31)
Morphine or morphine derivatives in combination with other drugs (excluding benzodiazepines)	4 (4)	4 (8)	2 (4)	10 (5)
All other drugs or combinations	5 (5)	1 (2)	0 (0)	6 (3)
<b>Terminal sedation used‡</b>				
Without the intention of hastening death§	35 (34)	17 (32)	23 (42)	75 (36)
Partly with the intention of hastening death§	51 (50)	25 (47)	24 (44)	100 (47)
With the explicit intention of hastening death§	17 (17)	11 (21)	8 (15)	36 (17)
<b>Explicit intention concerned§</b>				
Sedation	3 (3)	1 (2)	0 (0)	4 (2)
Forgoing artificial nutrition or hydration	14 (14)	7 (13)	8 (15)	29 (14)
Both sedation and forgoing artificial nutrition or hydration	0 (0)	3 (6)	0 (0)	3 (1)
<b>Estimated shortening of life  </b>				
No shortening or <24 h	36 (36)	23 (44)	22 (42)	81 (40)
1–7 d	40 (40)	16 (31)	11 (21)	67 (33)
1–4 wk	19 (19)	11 (21)	14 (27)	44 (21)
>1 mo	6 (6)	2 (4)	5 (10)	13 (6)
<b>Euthanasia discussed¶</b>				
	26 (25)	35 (66)	16 (29)	77 (37)
<b>Reasons euthanasia was not performed</b>				
Wish of the patient	4 (4)	11 (21)	4 (7)	19 (9)
No explicit patient request	5 (5)	8 (15)	3 (5)	16 (8)
Terminal sedation is palliative care, part of natural process of dying	6 (6)	3 (6)	0 (0)	9 (4)
No legal framework	3 (3)	3 (6)	0 (0)	6 (3)
Rapid dying process	1 (1)	3 (6)	2 (4)	6 (3)
Unknown/other	8 (8)	7 (13)	7 (13)	22 (10)

\* In 1 case, information on drugs used was missing.

† Possibly combined with other drugs.

‡ Forgoing artificial nutrition or hydration concerned the intention of "hastening death" or "not to prolong life."

§ Intention concerned either sedation or forgoing artificial nutrition or hydration.

|| In 6 cases, information on estimated shortening of life was missing.

¶ In 1 case, information on whether euthanasia was discussed was missing.

patients receiving artificial nutrition and hydration were excluded. Other studies used less restrictive definitions. Some included moderately sedated patients, some included a majority of patients who were sedated intermittently, and none excluded patients receiving artificial nutrition and hydration (4, 5, 20–24, 26).

Clinical specialists performed half of all cases of terminal sedation, although they attended 35% of the total number of deaths in the Netherlands. Apparently, terminal sedation is more often practiced in a hospital than at home. This may be explained in part by the fact that in-hospital

patients (especially those with cancer or cardiovascular disease) more often have severe symptoms or extreme exacerbations of conditions.

The sample of physicians' most recent cases of terminal sedation included about equal proportions of both sexes. Approximately one third of all deaths resulting from terminal sedation were in patients 80 years of age or older, whereas 46% of all deaths in the general population occurred in this age group (33). The major reasons for using terminal sedation were to alleviate severe pain, agitation, dyspnea, and anxiety. In a review of 17 studies that ad-

dressed the use of sedatives in the care of patients with cancer who were in the final stages of life, a syndrome of delirium and agitation was the most frequently mentioned indication for sedative use; pain was a much less common reason for sedation (21). However, most of these studies did not take into account the use of opioids. In addition, patients in some of these studies were only moderately sedated.

In our study, terminal sedation was performed with benzodiazepines in 60% of the most recent cases seen by physicians and with morphine or morphine derivatives in the remaining most recent cases seen. Other studies also found that benzodiazepines were most commonly used for deep sedation in patients nearing death. The use of opioids alone for deep sedation is regarded as less effective than the use of sedatives and may even be counterproductive (8, 21, 22). Cherny and Portenoy have produced guidelines for the use of sedation for controlling symptoms; in their opinion, benzodiazepines are the most favored class of sedatives in palliative care worldwide (34). Some researchers suggest that opioid use for relief of pain and other symptoms should be continued when sedation is being instituted to avoid the possibility of unobservable pain or symptoms of opioid withdrawal (8). Opioids are frequently used in hospital settings to treat pain and other symptoms. The relatively high proportion of morphine-induced cases of terminal sedation in our study may indicate that unconsciousness was a consequence of pain and symptom management or of progression of the underlying disease.

In our study, terminal sedation was almost always discussed with relatives but not always with the patient, who was often no longer communicative. A remarkable finding was that general practitioners were much less likely to consult other physicians or caregivers. In addition, the physicians in our study rarely consulted specialists in palliative care from other institutions and rarely consulted pain management teams. General practitioners were less likely to involve nurses in decision making about terminal sedation than were other physicians. This may reflect the fact that nurses are less available to general practitioners than to physicians working in institutional settings.

If life-sustaining treatment, such as artificial nutrition or hydration, is forgone in patients nearing death, death will usually occur within a short time. However, in our study, 36% (CI, 29% to 42%) of the physicians made their most recent decision to perform terminal sedation without the intention of hastening death. The physicians partly had the intention to hasten death in 47% (CI, 41% to 54%) of cases and the explicit intention to hasten death in 17% (CI, 13% to 22%) of cases. In most reported cases, this explicit intention concerned the decision not to give artificial nutrition or hydration. The estimated shortening of life was limited to less than 1 week in 73% (CI, 67% to 79%) of the cases most recently seen by physicians, indicating that the practice of terminal sedation is not restricted to patients for whom death was imminent.

When making the decision to perform terminal sedation, the physician may have considered euthanasia, that is, the administration of drugs with the explicit intention to end life at the patient's request. The Dutch euthanasia law was enacted in 2002, but from the early 1990s, physicians who met the official criteria for prudent practice were not prosecuted for performing euthanasia. Euthanasia was discussed in the course of the decision-making process in about 40% of the cases. Physicians reported that the main reasons for choosing terminal sedation rather than euthanasia were the patient's preference for terminal sedation to euthanasia and the patient's belief that terminal sedation was less intrusive than euthanasia on the natural dying process. In some cases, the physicians reported that euthanasia could not be performed because the patient did not fulfill the requirements (for example, an explicit patient request for euthanasia) of prudent practice for euthanasia. In general, there was a lack of explicit request when the patient was incompetent or moribund.

In the Dutch context, there are some obvious ethical and practical differences between terminal sedation and euthanasia. By definition, euthanasia is the result of an explicit request of the patient. Such a request is not necessary for terminal sedation. However, the presence (33% in our study) or absence of a patient's request or at least discussion with the patient (59% in our study) can be important in the justification of terminal sedation. With euthanasia, patients die as a result of the administration of lethal drugs. By contrast, with terminal sedation, patients die naturally as a result of their disease (this is most likely when death occurs in a few days), as a result of forgoing artificial nutrition or hydration (when death occurs after more than a few days), or as a result of the administration of sedatives. In addition, physicians always use euthanasia with the explicit intention of hastening death, whereas hastening death is the primary intent in only a fraction of terminal sedation cases. Researchers have shown that approximately 2.6% of all deaths in the Netherlands are preceded by euthanasia; 20% are preceded by the alleviation of pain or symptoms; and 20% are preceded by decisions to withhold or withdraw potentially life-prolonging treatments (33). Cases of terminal sedation in which hastening of death was not intended or taken into account cannot be considered to represent either of these end-of-life decisions. When physicians prescribe sedatives with the explicit intention of hastening death, their actions may be regarded as intentional ending of life.

Our study has several limitations. First, face-to-face interviews may be biased by interviewer interpretation. Moreover, the respondents may have felt obligated to give socially acceptable answers. 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 difficulty 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 term “terminal sedation” can evoke different connotations and interpretations in respondents. We tried to avoid this problem by providing a very specific definition of the term. Last, our findings may not be generalizable to other countries because of the openness in Dutch society about end-of-life issues.

We conclude that terminal sedation precedes a substantial number of deaths in the Netherlands. Terminal sedation is an option that is used to alleviate severe symptoms in the last phase of life; in most cases, it shortens life to less than 1 week. According to our reports about physicians’ most recent cases, terminal sedation is usually provided after discussion with the patient, relatives, and caregivers. In a limited number of cases, when the physician administers a sedative with the explicit intention to hasten death at the explicit request of the patient, terminal sedation seems to approximate the practice of euthanasia.

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## 2004 PERSONAE PHOTOGRAPHY PRIZE

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## Questionnaire F: Terminal Sedation: Frequencies and Case Characteristics

### Introduction

In some cases, patients are deeply sedated or are put into an induced coma prior to death with the help of medications such as benzodiazepines or barbiturates. This may or may not include forgoing nutrition and/or hydration.

F1a Have you ever sought to alleviate pain or other symptoms in a terminally ill patient by deep sedation or by putting him or her into coma?

- ◆  Yes
- ◆  No → go to question F2a

F1b When was the last time you did so?

 Month

*Be as precise as possible*

*If before 1-1-2000 → go to question F2a*

 Year

F1c In how many patients did you do so in 2001?

 Patients

*i.e. between 1-1-2001 and 31-12-2001*

F1d In how many patients did you do so in 2000?

 Patients → go to question F3a

*i.e. between 1-1-2000 and 31-12-2000*

F2a Are there conceivable situations in which you would apply deep sedation to a patient prior to his or her death?

- ◆  Yes
- ◆  No → go to question F2c

F2b Can you describe such a situation?

→ go to questionnaire G

F2c Why not?

→ go to questionnaire G

Throughout the questionnaire, phrases indicate that the respondent should be allowed to look at a particular card. Some questions include the use of cards with the possible answers for a particular question. The respondent can read the possible answers from the card and then choose the corresponding answer. ALS = amyotrophic lateral sclerosis; COPD = chronic obstructive pulmonary disease; CVD = cardiovascular disease; MS = multiple sclerosis.

F3a Have you ever made the decision to forgo nutrition and/or hydration in a deeply sedated patient \*?

- ◆  Yes
- ◆  No → go to question F4a

*\*Note: no hydration and/or nutrition or only in severely limited quantities, i.e., not enough to sustain life.*

F3b When did you last do so?

Month

*Be as precise as possible  
If before 1-1-2000 → go to question F5*

Year

F3c In how many patients did you do so in 2001?

Patients

*i.e. between 1-1-2001 and 31-12-2001*

F3d In how many patients did you do so in 2000?

Patients

*i.e. between 1-1-2000 and 31-12-2000  
→ go to question F5*

F4a Are there conceivable situations in which you would forgo nutrition and/or hydration in a deeply sedated patient \*?

- ◆  Yes
- ◆  No → go to question F4c

*\*Note: no hydration and/or nutrition or only in severely limited quantities, i.e., not enough to sustain life*

F4b Can you describe such a situation?

→ go to questionnaire G

F4c Why not?

→ go to questionnaire G

## Questionnaire F: Terminal sedation, Case

### Introduction

I would now like to ask you a number of questions about the last time (regardless of when this happened) you practiced deep sedation on a patient prior to death while forgoing artificial nutrition and/or hydration, or giving artificial nutrition and/or hydration in quantities that were not sufficient as to sustain life.

I would like to start with a few questions about the patient

F5 Can you give a very brief description of the case?

*This question is designed to have the respondent provide a summary introduction of the case and to establish whether this was indeed a case in which a patient was deeply sedated prior to death, to whom no or only very limited quantities of nutrition or hydration were administered.*

F6 What was the main diagnosis?

- ◆  Lung cancer
- ◆  Colon cancer
- ◆  Prostate cancer
- ◆  Stomach cancer
- ◆  Breast cancer
- ◆  Pancreas cancer
- ◆  Cancer, other, namely:
  
- ◆  AIDS
- ◆  CVD
- ◆  Heart failure
- ◆  MS
- ◆  ALS
- ◆  COPD
- ◆  Old age/general deterioration
- ◆  Other, namely:



F7 Approximately how long had this patient been registered in your practice?

*Mention possible answer categories*

- ◆  < 1 month
- ◆  1-3 months
- ◆  4-6 months
- ◆  7-12 months
- ◆  1-5 years
- ◆  > 5 years

F8 How old was the patient when he/she died?

- ◆  Man  Years
- ◆  Woman  Years

**I would now like to ask you a number of questions about the treatment of the patient at the time of the decision making about deep sedation.**

F9a What was the aim of the treatment at that moment?

*Tick one or more answers*

*Mention possible answer categories*

- Cure
- Prolonging life
- Palliation (namely not aimed at prolonging life)
- Other, namely:

F9b Were there at that moment any realistic curative or life-prolonging treatment options available?

- ◆  Yes
- ◆  No → go to question **F10a**

F9c Why did the patient not receive this/these treatment options?

*Tick one or more answers*

- Patient did not want to
- Too little chance of improvement
- Severity of expected side effects
- Treatment was too much of a burden
- Other, namely:

Let the respondent look at card F1

F10a Can you indicate, on a 5-point scale, the extent to which the following signs or symptoms (in spite of any treatment) were present in this patient at the time of the decision making about deep sedation?

	1	2	3	4	5	
No pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Severe pain
No decubitus	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Severe decubitus
No obstipation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Severe obstipation
Not nauseous	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Very nauseous
Not coughing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Coughing a lot
Not vomiting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Vomiting a lot
Not depressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Very depressed
Not afraid	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Very afraid
Not tired	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Very tired
Not confused	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Very confused
Clearly conscious	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Not clearly conscious
Good appetite	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Very little appetite
Not short of breath	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Very short of breath
Very active	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Not active
Feeling well	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Feeling ill

F10b Was the patient treated for pain?

*Tick one or more answers*

- No
- Yes, with oral morphine
- Yes, with rectal morphine
- Yes, with morphine injections
- Yes, with morphine (fentanyl) plasters
- Yes, with a morphine pump
- Yes, with medication other than morphine, namely:

F10c Was the patient treated at that time for nausea or vomiting?

- ◆  No
- ◆  Yes, with:

F10d Was the patient treated at that time for dyspnea?

- ◆  No
- ◆  Yes, with:

F10e Was the patient treated at that time for depression?

◆  No

◆  Yes, with:

F10f Was the patient treated at that time for confusion?

◆  No

◆  Yes, with:

F10g Was the patient treated at that time to relieve other complaints or symptoms?

◆  No

◆  Yes, with:

F11a What was the reason for deeply sedating the patient?

*Tick one or more answers*

Pain

Agitation

Dyspnea

Other symptoms, namely:

F11b To what extent, in your opinion, was the suffering of the patient unbearable at the time of the decision making about the deep sedation?

◆  To a great extent

◆  To a certain extent

◆  To a lesser extent

*Mention possible answer categories*

F11c To what extent, in your opinion, was the suffering of the patient hopeless at the time of the decision making about the deep sedation?

◆  To a great extent

◆  To a certain extent

◆  To a lesser extent

*Mention possible answer categories*

F12a Did the patient regain consciousness at any time following the initiation of deep sedation?

◆  Yes

◆  No → go to question **F13a**

F12b What was the reason for or cause of this?

*Tick one or more answers*

- Dosage provided insufficient sedation
- For consultation about further decision making
- Possibility of contact with family/relatives
- To administer nutrition and/or hydration
- Other, namely:

F13a In making the decision to apply deep sedation, was the possibility or the certainty that this could hasten death taken into account?

- ◆  Yes
- ◆  No → go to question **F14a**

F13b Was sedation administered:

*Let respondent now look at card F2*

- ◆  Without the intention to hasten death  
→ go to question **F14a**
- ◆  Partially with the intention of hastening death  
→ go to question **F13c**
- ◆  With the explicit intention to hasten death  
→ go to question **F14a**

F13c What do you mean by “partially with the intention”?

*Tick one or more answers*

- There was a more important intention, namely:

- I accepted the additional effect of hastening death, but it was not my intention
- My intention was also to hasten death
- Other, namely:



**I now want to ask a few questions about the medication that was used for the sedation**

*Let respondent look at card F3*

F14a Which medication was given to bring the patient in deep sedation? (in sequence of administration):

		Medication 1	Medication 2
F14b	Name of the medication		
F14c	Method of administration		
	Oral	<input type="checkbox"/>	<input type="checkbox"/>
	Rectal	<input type="checkbox"/>	<input type="checkbox"/>
	Intravenous	<input type="checkbox"/>	<input type="checkbox"/>
	Other	<input type="checkbox"/>	<input type="checkbox"/>
F14d	Amount in the final 24 hours		
		mg	mg

**The following questions concern the nutrition and hydration policy**

*Let respondent now look at card F4*

F15a Was the decision to forgo nutrition and/or hydration, or to administer this in only very limited quantities taken:

- ◆  Without intending to hasten the end of life \*  
→ go to question **F16a**
- ◆  Partially with the intention of hastening the end of life \* → go to question **F15b**
- ◆  With the explicit intention to hasten the end of life \* → go to question **F16a**

*\* Note: "to hasten the end of life" or "not to prolong life"*

F15b What do you mean by "partially with the intention"?

*Tick one or more answers*

- There was a more important intention, namely:
- I accepted the additional effect of hastening death, but it was not my intention.
- My intention was also to hasten death.
- Other, namely:

F16a Did the patient forgo or receive limited quantities of hydration and/or nutrition throughout the period of deep sedation prior to death?

*Tick one or more answers*

- Limited nutrition → go to question **F16b**
- Limited hydration → go to question **F16b**
- No nutrition, no hydration → go to question **F16c**

F16b With what intention were limited amounts of nutrition and/or hydration administered?

*Tick one or more answers*

- Compliance with the request of family or relatives
- Reassurance of family or relatives
- Compliance with a request from nursing staff
- The patient's comfort
- Alleviation of symptoms, namely:

- Precautionary IV line
- Other, namely:

F16c How long after the initiation of the (final period of) continuous deep sedation was it decided to forgo or to administer only limited amounts of nutrition and/or hydration?

- ◆  Simultaneously
- ◆  After  hours
- ◆  After  days
- ◆  After  weeks
- ◆  After  months

**I would now like to ask you a number of questions about your decision-making process. First about the deep sedation and subsequently about the forgoing of nutrition and/or hydration.**

F17a Did you, or another physician, discuss the decision to apply deep sedation with the patient?

- ◆  Yes → go to question **F17c**
- ◆  No

F17b Why did you not discuss this with the patient?

*Tick one or more answers*

- Patient was not (no longer) fully lucid
- Patient was too young
- Patient suffered from dementia
- Patient was mentally disabled
- Patient had a psychiatric disorder
- Patient was subcomatose
- The proposed course of action was clearly the best for the patient
- Discussion would do the patient more harm than good
- Other, namely:

→ go to question **F18a**

F17c Did the patient request deep sedation?

*Let respondent now look at card F5*

- ◆  Yes
- ◆  No → go to question **F18a**

F17d What were the most important reasons for the patient to make his or her request?

*Tick one or more answers*

- Pain
- Dyspnea
- Other symptoms, namely:

- Humiliation/loss of self-esteem
- General weakness/fatigue
- Tired of life
- No reason to suffer anymore
- Suffering with no hope of improvement
- Vomiting
- Fear of suffocating
- Invalidity/immobility
- Depression
- Dependence
- Not (or no longer) wanting to be a burden on family/environment
- Other, namely:

F18a Did you discuss the sedation with other caregivers?

- ◆  Yes
- ◆  No → go to question **F18c**

Let respondent now look at card **F6**

F18b Who were the caregivers with whom you discussed?

Tick one or more answers

- Colleague physician in my own field
- Colleague physician in a different field, namely:

- Nursing staff
- Specialists in palliative care from other institutions
- Pain Management Team
- Other, namely:

F18c Did you discuss the sedation with the family and/or relatives?

- ◆  Yes
- ◆  No → go to question **F19a**

F18d Had there been a request to this effect from the family and/or relatives?

- ◆  Yes
- ◆  No

F19a Did you or another physician discuss the decision to forgo, or to administer only limited amounts of nutrition and/or hydration, with the patient?

- ◆  Yes → go to question **F19c**
- ◆  No

F19b Why did you not discuss this with the patient?

→ go to question **F20a**

F19c Did the patient request to forgo nutrition and/or hydration?

- ◆  Yes
- ◆  No → go to question **F20a**



F19d What was the reason for the patient's request?

F20a Did you discuss with other caregivers whether or not to forgo nutrition and/or hydration?

- ◆  Yes
- ◆  No → go to question **F20c**

F20b Who were the caregivers with whom you discussed?

*Tick one or more answers*

- Colleague physician in my field
- Colleague physician in a different field, namely:

- Nursing staff
- Specialists in palliative care from other institutions
- Pain Management Team
- Other, namely:

F20c Did you discuss the forgoing of nutrition and/or hydration with the family and/or relatives?

- ◆  Yes
- ◆  No → go to question **F21a**

F20d Had there been a request to this effect from the family and/or relatives?

- ◆  Yes
- ◆  No

F21a Had euthanasia or assisted suicide ever been a subject of discussion with this patient?

- ◆  Yes
- ◆  No → go to question **F22**

F21b Why was euthanasia or assisted suicide not performed?

F22a How long after the initiation of (the final period of) continuous deep sedation did the patient die?

- ◆  After  hours
- ◆  After  days
- ◆  After  weeks
- ◆  After  months

F22b In your opinion, by how much time was the patient's life shortened by the combination of deep sedation and the forgoing, or administration of very limited quantities, of nutrition and/or hydration?

*Mention possible answer categories*

- ◆  More than half a year
- ◆  One to six months
- ◆  One to four weeks
- ◆  A week, at the maximum
- ◆  Less than 24 hours
- ◆  Probably did not have any life-shortening effect

F23 Reviewing the situation as a whole, how do you think your actions affected the quality of the patient's end of life?

*Tick one or more answers*

- Improved end-of-life quality
- Had little effect
- Don't know, haven't thought about it
- Don't know, hard to assess
- Other, namely: