

Terminal Sedation: A Legal Approach

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Introduction

In many cases, medical end-of-life decisions precede dying. Such decisions, ranging from the alleviation of pain and symptoms and non-treatment decisions to the administration of drugs with the explicit intention of hastening death, seem to occur everywhere, although the frequency of the different types of decisions varies considerably between countries.¹

These different types of decisions have been debated extensively in the international medical, legal and ethical literature. Usually, measures to alleviate pain are considered the least controversial. Even if such a measure may have as a side effect that the patient dies sooner, this is generally considered an acceptable consequence, as long as the physician did not aim at hastening the patient's death, the side effect is not excessive and the measures taken are justified by the objective to reduce pain and suffering.

Decisions to withhold or to withdraw treatment (including life support) have received much more critical attention, as is demonstrated by court decisions in many countries for instance on non treatment of severely handicapped newborns, or on ending artificial feeding of patients in a persistent vegetative state. This is understandable for several reasons: when death is the foreseeable consequence of a non treatment decision, the decision not to act looks very similar to active termination of life. If withholding of treatment cannot be based on the patient's own deliberate and well informed choice, it needs to be justified on medical grounds, i.e. that (further) treatment is pointless or futile, or at least disproportional taking into account the medical situation of the patient. Especially the last situation may easily give rise to debate, in particular regarding the question to what extent the overall 'quality of life' of the patient may be the basis for withholding treatment.

Most controversial are measures (like administration of drugs) which are taken with the direct intention of hastening death, either on the explicit request of the

patient (voluntary euthanasia), or without such a request as a medical response to severe suffering that cannot be relieved by less drastic means. Whereas the latter decision is likely to lead to prosecution in all jurisdictions (although a doctor standing trial may be acquitted in exceptional cases, for instance on the basis of a conflict of duties), euthanasia has been legalised in some countries (the Netherlands, Belgium), at least under strict conditions and safeguards.² In this case the principle of self determination plays an important role, in addition to the existence of hopeless and unbearable suffering. Nevertheless, in many countries active termination of a patient's life is not accepted at all (although some jurisdictions do accept physician assisted suicide, which may come very close to euthanasia).

In the last five to ten years there has been increasing debate on a medical practice at the end-of-life that is difficult to place between the aforementioned end of life decisions. This practice is called terminal sedation, although other concepts are used as well (palliative sedation; deep sedation). Terminal sedation is the administration of sedative drugs with the aim to reduce the consciousness of a terminal patient in order to relieve distress; it is frequently accompanied by the withdrawal (or withholding) of life sustaining interventions, such as hydration and nutrition. It is typically a measure of the last resort to be considered in situations where all other measures to reduce pain and suffering have failed.³

While similar to palliative measures as far as the sedation itself is concerned, withholding of hydration and nutrition brings terminal sedation into the realm of non treatment decisions. At the same time, to the extent that the combination of these two measures may shorten the patient's life, the practice may be easily associated with euthanasia. It is no surprise, therefore, that terminal sedation has been called (and has been disqualified as) 'slow euthanasia' or 'backdoor euthanasia', suggesting that it should be dismissed as a covert form of a practice which is by many already considered as unacceptable per se.⁴

The question in this article is how terminal sedation may be looked upon from a legal point of view. Is it indeed a disguised form of euthanasia, or should it be considered as a practice in its own right? In the latter case, what does it imply in legal terms, and under which conditions and safeguards could it be legally justified?

In addressing these questions we will have to look first at the different clinical realities that may be brought under the heading 'terminal sedation'. Subsequently the results of a recent survey of (inter alia) terminal sedation in the Netherlands will be reported. The next section deals with the two components of terminal sedation – sedation on the one hand, and withholding artificial nutrition and feeding on the other – in a legal perspective. The article ends with conclusions on terminal sedation as a whole.

One concept, different practices

At the end of life, terminally ill patients may suffer from intolerable symptoms that are refractory to the usual palliative measures. Such symptoms cannot only be pain, but also shortness of breath (dyspnoea), persistent unrest (delirium), irrepressible vomiting etc.; in addition to physical distress, also uncontrollable psychological suffering may occur.⁵ In case of intolerable and refractory suffering, adequate relief is only possible by inducing sedation and reducing the consciousness of the patient to a level required to manage the patient's distress. In many cases this means that sedation is deep and more or less continuous.

Terminal patients are not eating or drinking substantial amounts; the patients that are considered for deep sedation are not likely to eat and will hardly drink. Although artificial hydration and nutrition would seem indicated when the patient is no longer able to eat and drink himself, in some patients – in particular those already dying – it will be contraindicated because it would only lengthen the dying process. In others – apart from the risk of pulmonary edema and other adverse effects – it may be withheld either on the basis of an explicit refusal of the patient, or because in the final analysis the patient – taking into account his intolerable situation and the inevitability of an imminent death – has nothing to gain from it.

In many cases, there is no reason to believe that life is shortened by terminal sedation (even if it includes dehydration); according to several authors, sedation may sometimes even prolong the life of the patient. In other cases, however, in particular when the patient may still live for weeks, a life shortening effect cannot be excluded when deep sedation is not combined with artificial nutrition or at least hydration.

These different clinical realities – together with different views on the ethical merits of the practices in question – have given rise to different definitions. Some authors object to the concept 'terminal sedation', most often because the term suggests it is about terminating the life of the patient. To avoid this, other terms are proposed like deep sedation or palliative sedation. Another objection – this time against the usual definition of terminal sedation (including sedation as well as withholding nutrition/hydration) – relates to the inclusion of withdrawal of artificial feeding. While acknowledging that this may often occur, it is maintained that this is not inherent to sedation of terminal patients and that withholding or withdrawing life support is a different decision which requires separate justification. Although these arguments are valid, the term 'terminal sedation' is widely used for the practices that have been described. Since it will be hard to introduce another vocabulary, it makes little sense to use different terms.

This is not to say that one should not try to distinguish the different situations covered by the same qualification. When looking at clinical practice from an legal and ethical point of view, at least three situations are to be distinguished.⁶

In the first place there are patients with a life expectancy of not more than a few days. In quite a few cases, these patients are sedated to control a terminal delirium. Food and fluids are not administered, because usually these patients have stopped to eat and drink. There is even no need to take a decision on this point because the patient is already dying. Secondly, when death is not imminent, terminal sedation (including dehydration) may shorten the life of the patient due to the fact that he has a longer life expectancy (i.e. in terms of weeks, rather than in terms of days or even hours) although this possible effect is not intended. In that case the responsible physician needs to take a deliberate decision on the continuation or discontinuation of artificial feeding. Finally, terminal sedation may be used first of all with the intention to shorten the life of the patient, with or without his explicit request, and not as a means to control intolerable and refractory suffering in a terminal patient. Whereas the first case can be seen as a specimen of normal medical practice and the last one as a practice comparable to euthanasia (at least when on the request of the patient), the second one lies somewhere in between.

A recent survey

What about the extent to which terminal sedation (including all the above mentioned types) occurs? A recent nation wide study in the Netherlands on euthanasia and other end of life decisions provides some figures on the Dutch situation.⁷

In 4 to 10 % of all deaths terminal sedation took place. In most cases the reason for it (as mentioned by physicians) was relief of symptoms like pain, dyspnoea, restlessness etc. In the majority of cases the decision to sedate was discussed with the patient. When the patient was not involved, this was most often because communicating with the patient was difficult or impossible. For the same reason, in these cases also the decision to refrain from artificial feeding was not discussed with the patient; however, this last decision was also often perceived by physicians as a self-evident consequence of the sedation decision, and not as a decision in its own right. Sedation decisions were almost always discussed with the family, but only in less than half of the cases with fellow physicians or nurses. Hastening the patients death was not the intention of the patient in one third of all the cases of terminal sedation. In about half of them, it was a secondary aim next to relieve of pain or other symptoms. In 20 % of all cases, hastening the death of the patient was the explicit intention.

The above figures – and in particular the last ones concerning the relatively high number of cases in which shortening of the patient's life was not only taken for granted but intended – may not be applicable without modification to other countries where voluntary euthanasia is not allowed. In the Netherlands euthanasia (on the basis of an explicit request of the patient) takes place in about 2.6% of all deaths. According to the data of the same study, in a considerable part of the cases of terminal sedation, euthanasia had been mentioned in previous discussions with the patient about the care to be given in the terminal phase of his disease. That euthanasia was not performed was sometimes due to the fact that the patient preferred terminal sedation; more often, however, it was because other circumstances made euthanasia undesirable or impossible, for instance because there was no explicit request of the (by that time) incompetent patient to end his life.

The nation wide study that produced these figures was conducted under the auspices of an monitoring committee that commented briefly on the results of the report. As to terminal sedation, the committee concludes that in most cases terminal sedation is not an alternative to euthanasia, but part of palliative care at the end of life in order to alleviate the suffering of the terminal patient. However, according to the committee, where terminal sedation took place with the explicit intention to shorten the life of the patients the public authorities should have been notified. Under the new Dutch law on euthanasia, this means notification either of one of the regional review committees for the termination of life on request, or – where no request had been made – directly of the public prosecution.⁸

A legal appraisal

As this last report shows, the subjective intention of the physician plays an important role in how terminal sedation is qualified: as inherent to palliative care, or as similar to euthanasia. This is not strange, since – certainly from a philosophical point of view – intentions are important, and do make a difference in the ethical evaluation, both in case of acting and of omitting. In a legal perspective, however, although intentions are relevant they are not necessarily decisive. A physician may be held liable under criminal law, for instance, for the adverse consequences of his decisions if he did not take these consequences sufficiently into account, and not only if he intended them. The law does not exclusively rely on an internal state of mind and looks at human behaviour in a less subjective way. Did the behaviour in question affect an interest or a principle that is protected by the law? Could and should the person in question have foreseen that adverse consequence of his decisions? Should he have avoided it taking into account all the circumstances of the case?

In assessing the legal implications of terminal sedation, it is therefore not only relevant what the physician had in mind, but also whether what he did (deep sedation; eventually refraining from artificial feeding) was necessary and adequate to protect the patient from (further) suffering and not disproportionate with a view to the farreaching consequences of his decisions.

Secondly, in order to evaluate terminal sedation from a legal point of view, it is important to make a distinction between sedation on the one hand and withholding of artificial hydration and nutrition on the other. The induction of unconsciousness and the withdrawal of life-sustaining medical intervention must be seen as separate decisions supported by different legal and ethical principles.⁹ Apart from this normative difference, the distinction has also a factual basis: there is no medical ground why sedation should always go together with dehydration and non-feeding. While the combination is evident in dying patients, it is much less so in other cases.

Traditionally, palliative measures with life shortening effect have been justified by the principle of double effect. According to this principle, consequences that would be wrong if caused directly and intentionally, become acceptable if the actions they result from are carried out for a morally good purpose.¹⁰ Even if the wrong consequences are foreseen, they may be justified when they cannot be avoided in reaching the good purpose and when that purpose outweighs the bad, non-intended side effects. The same theory has also legal significance; it underlies in particular the doctrine of the medical exception. According to this doctrine, physicians are not liable for causing foreseeable harm to the patient, to the extent that this is necessary to realise more important medical benefits, provided the patient or his surrogate has consented and the decisions of the physician are carried out in accordance with the professional standard. On this basis, for instance, a surgeon performing an operation on a patient will not be criminally responsible for cutting the skin and opening the patient's body.

The administration of drugs to relieve pain is a long standing and accepted clinical practice, also in cases where it might hasten the death of the patient. What the law requires in such a case is not only (and not even in the first place) that the doctor did not intend to shorten the patient's life, but first of all that what he does is necessary, adequate and not excessive with a view to the alleviation of suffering.

The same argument applies to sedation of patients in a terminal phase. That means also that the degree of sedation should be commensurate to what the situation of the patient requires in terms of palliative care. Terminal sedation is not necessarily deep, continuous and unreversed sedation. Nevertheless, sometimes total and continuous loss of conscience may be necessary to relieve suffering. In that case sedation separates the physical dimension of the patient's existence from the mental and social ones, and takes the latter dimensions away. Although this

consequence is substantial, there is no reason why it could not be justified on the same basis as other palliative measures, provided it is the only way to relieve intolerable and refractory symptoms.

What is always required, however, is that a palliative measure like deep sedation is discussed with the patient, including its consequences in terms of the impossibility of eating and drinking spontaneously and the possible effects that may have on the patient's survival. If the patient is not competent, his or her partner or relatives (or other surrogates designed by the law) should be consulted. Unless the patient is opposed to it, it is appropriate to involve them anyway, so that they know what is happening and can say farewell to their loved one.

The most controversial aspect of terminal sedation is the fact that in practice it is very often combined with withdrawal or withholding of hydration and nutrition. As has been explained before, this may have a life shortening effect, but this certainly need not be the case. For some patients death will be so imminent that artificial feeding or hydration is not a real option and that not even dehydration is likely to affect the moment of death. The ethical and legal questions rather arise in the setting of terminal patients with weeks to live.¹¹ See also the distinction made among the three situations in Section 2.

How to evaluate withholding food and fluids in that situation from a legal point of view?

First of all, it goes without saying that the competent and well informed patient can refuse artificial hydration and nutrition. If the patient has not been able to discuss the matter with his doctor and there is no more an advance directive on this point, decisions become a matter of careful clinical judgement. The attending physician should discuss his decision with the partner or relatives (or other surrogates). At the same time, he cannot simply let them decide. In a situation of life and death, the physician should be satisfied himself that what is done or omitted is in the best interest of the patient.

It is possible that even if the death of the patient is not imminent, continuation of feeding and providing fluids is no longer indicated, and becomes disproportional or even pointless taking into account the overall situation of the terminal patient. In particular, providing nutrition and hydration may only lengthen a life which is only bearable due to continuous deep sedation. However, withholding of hydration and nutrition after deep sedation should certainly not be standard practice. It would be even misleading to state that one is only sedating the patient if at the same time knowingly and willingly vital fluids are withheld in a situation where this is likely to shorten the patient's life.¹² In that case a separate justification is required, which can either be based on the explicit wish of the patient to forego artificial feeding and hydration, or on the fact that according to careful medical judgement it does no longer serve a reasonable goal taking into account the situation of the patient.

Conclusions

Should terminal sedation be considered a disguised form of euthanasia? As set out in the preceding sections, it is about sedation (and eventually withholding food and fluids) in a terminal phase, not about hastening death. Unlike euthanasia, it has not per definition a life shortening effect; what the physician aims at is controlling intolerable and refractory symptoms. But intention is not the only thing that matters. What is crucial is that what the physician does is in line with that objective: the dosage of the drugs administered should be in accordance with what is needed for symptom control. Dehydration (and refraining from artificial feeding) should not be a self evident part of sedation but be justified as a separate decision, in particular where death is not imminent and the patient may live for more than a few days.

Also if these conditions are met, however, terminal sedation is an extreme measure of symptom control and in some situations the line between what is and is not responsible medical care may be thin. Although in principle it can be a form of good clinical practice, at the same time fundamental values are at stake. This means that the practice of terminal sedation should be transparent and that physicians are accountable for that practice. It is crucial that diagnostic and prognostic clarity with respect to the patient's disease and anticipated life span is ensured.¹³ Furthermore, whenever possible terminal sedation is to be discussed with the patient himself. Finally, society may justly require that procedural safeguards are in place, including sufficient documentation and a second opinion in cases where death is not imminent. What is needed is not so much specific legislation, but authoritative clinical guidelines providing a workable protocol on how physicians should proceed. That would also show that terminal sedation can be part of accepted palliative care and that it can be practised in a way consistent with the law.¹⁴

Notes:

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1. A. van der Heide et al., End of life decision-making in six European countries: descriptive study, *The Lancet*, published on line June 17, 2003.
2. For the Netherlands see *Eur.Jnl. of Health Law* 8; 2001: 183-191 (The Netherlands: the new Dutch law on Euthanasia).
3. R.McStay, Terminal sedation: palliative care for intractable pain; post Glucksberg and Quill, *Am.Jnl. of Law and Med.* 29; 2003: 45-76.
4. D.Orentlicher, The Supreme Court and physician-assisted suicide – rejecting assisted suicide but embracing euthanasia, *NEJM* 337; 1997: 1236-1239.

5. B. Broeckaert, J.M. Nunez Olarte, Sedation in palliative care: facts and concepts, in: H. ten Have, D. Clark (ed.), *The ethics of palliative care; European perspectives*, Open University Press 2002, 166-180.
6. I am following here the distinction made by J.H.van Delden, *Medicine based ethics*, University of Utrecht, 2003.
7. G. van der Wal et al., *Medische besluitvorming aan het einde van het leven (Medical decision making at the end of life)*, De Tijdstroom, Utrecht 2003; I am giving the outcome of the survey as described on pp. 85-86 of the report.
8. *Medische besluitvorming aan het einde van het leven (Medical decision making at the end of life)*, Verslag van de begeleidingcommissie (Report of the monitoring committee), Ministry of Health, The Hague 2003.
9. See, R. McStay, o.c., p. 46.
10. Idem, p. 53.
11. B. Broeckaert et al., o.c. 172.
12. Idem, p. 171.
13. T. Quill et al., *Palliative options of the last resort; a comparison of voluntary stopping eating and drinking, physician assisted suicide, and voluntary active euthanasia*, JAMA 278 (1997) 2099.
14. R. McStay, o.c., p. 76.

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