

Terminal sedation

Health Council of the Netherlands

Centre for Ethics and Health

Alex Bood

The Hague, June 29, 2004

Centre for Ethics and Health

The Centre for Ethics and Health (Dutch abbreviation CEG) is a joint venture of the Health Council (*Gezondheidsraad*) and the Council for Public Health and Health Care (*Raad voor de Volksgezondheid en Zorg*). Under this heading, both advisory councils produce short 'alerts', identifying developments that, from an ethical point of view, merit the government's attention. These are intended to serve as building blocks for the Health Ministry's 'Ethics and Health' policy agenda, which is appended to the national budget each year in September.

The CEG's annual 'Ethics and Health Monitoring Report' (in Dutch) provides a compilation of these alerts. In June 2004, the second of these monitoring reports was presented to the State Secretary of Health. It contains alerts on seven topics, including the one on Terminal sedation presented here in translation.

Via its website www.ceg.nl the CEG also functions as a source of information on ethical issues in the field of (public) health.

This report

This report has been drawn up by the Health Council's Standing Committee on Medical Ethics and Health Law (see Appendix 1 for composition).

Author: Alex Bood, scientific secretary of the Standing Committee on Medical Ethics and Health Law.

Preferred citation:

Health Council of the Netherlands. Terminal sedation (Ethics and Health Monitoring Report 2004 no. 2). The Hague: Health Council of the Netherlands, 2004. Publication no. 2004/12-02E. ISBN: 90-5549-586-7.

This publication can be downloaded from www.healthcouncil.nl.

Contents

	Summary	5
	Terminal sedation	7
1	Introduction	7
2	Normal medical practice or termination of life	8
2.1	Importance of a clear definition	8
2.2	Causes of confusion.....	9
2.3	Sedation with a life-shortening effect	10
2.4	Withholding of artificially administered food and fluid with a life-shortening effect	12
2.5	Medical-professional grounds as distinguishing criteria	13
3	Proper care	15
3.1	Principles	15
3.2	Medical indication, subsidiarity and proportionality	17
3.3	Autonomy of and communication with the patient.....	18
3.4	Relatives.....	19
3.5	Consultation.....	20
3.6	The medico-technical aspects of due care.....	20
3.7	Reporting	21
4	Clinical practice	21
4.1	Frequency and classification	21
4.2	Due care.....	25
5	Implications for public policy	26
	Bibliography	29
	Appendix 1	33
	Standing Committee on Medical Ethics and Health Law.....	33

Summary

Terminal sedation is the procedure whereby a patient is placed into a deep sleep with the expectation that this will be maintained until he or she dies. Artificial administration of food and fluid is often withdrawn at the same time. This leads to a marked decline in the patient's consciousness up till death, and may also shorten his or her life. It is important that fundamental values and norms are not violated during this process, and that the patient continues to be treated with due care. This report indicates that opportunities for monitoring and encouraging this process will increase if terminal sedation administered on sound medical grounds is regulated by the medical profession itself on the basis of its own standards. This means that if terminal sedation has a life-shortening effect, then the physician's 'intention' when taking this action is no longer a decisive factor in deciding whether or not the physician has (criminally) ended the patient's life.

Terminal sedation

1 Introduction

People with a serious fatal disease often need special palliative care in the last phase of their life. The purpose of this care is to make it as easy as possible for them to bear and cope with the burden of their condition. Morphine is often administered to counter pain and other symptoms. This palliative care is often stepped up as the patient's condition worsens and his or her pain increases, but it does not always have the desired effect. It may be decided to sedate the patient if he or she seems to be suffering too much pain and is also anxious and restless. This sedation may initially be light and temporary depending on the circumstances, but may later on be intensified, or it may be decided that deep, permanent sedation is immediately required. Deep sedation that is expected to be maintained until the patient's death is referred to as 'terminal sedation'. The term 'palliative sedation' is often used as well, clarifying that this is often the final piece in a process of palliative care. Artificial administration of food and fluid is usually withdrawn at the same time because it no longer makes sense to provide it.¹

Terminal sedation is coming increasingly into the spotlight of debate. However, the conceptual and ethical discussion of this issue is still at a very early stage in the Netherlands (Janssens 2003, Willems 2003). The most recent assessment of the euthanasia review procedure did indeed first investigate the practice of terminal sedation (Van der Wal 2003). The report found that it was a relatively common procedure and sometimes took the form of euthanasia. A discussion was instigated as a result of this to look at a number of issues, including, among others, the question of whether terminal sedation should be brought within the remit of the review procedure for euthanasia (De Wijkerslooth 2003, Swart 2003, Van Dam 2003, Verhagen 2004).

One of the reasons for launching this debate was concern as to whether terminal sedation is administered with due care. This concern does not rest on any evidence of a serious lack of due care, but on three areas of uncertainty. The first area of uncertainty is how terminal sedation can be made a more transparent process and more open to review. These conditions are essential in order to allow the degree of care with which terminal sedation is administered to be monitored and, where necessary, improved. Second, the circumstances under which terminal sedation is also

¹ See Verhagen 1999 for a description of some practical cases of terminal sedation. The term 'terminal sedation' is used in this report as meaning the combination of sedation and suspension of artificial administration of food and fluid, unless it is clear from the context that this is not the case.

proper care are unclear. The debate about this has not yet crystallised. Finally, our understanding of the clinical practice of terminal sedation still remains limited.

This report indicates how these three areas of uncertainty can be resolved, and shows the consequences for public policy. First of all, the question of when terminal sedation can be regarded as 'normal medical practice' will be addressed (§ 2.2). This question must be clarified before the intervention can become transparent and open to review. We then look at the issue of when terminal sedation is also proper care (§ 2.3). We then explain why the findings of Van der Wal *et al* do not yet represent a clear image of the practice of terminal sedation. We indicate how more light can be thrown on the extent to which terminal sedation meets the requirements of normal medical practice and can be regarded in practice as proper care (§ 2.4). We end by setting out the implications for public policy (§ 2.5).

2 Normal medical practice or termination of life

2.1 Importance of a clear definition

Physicians must act in a transparent and verifiable manner to prevent fundamental values and norms being violated when terminal sedation is carried out and to allow this process to be monitored to ensure that standards of care are upheld or, if necessary, improved. The first condition for this is that it must be clear to physicians which review system governs the process. They must be confident that the criteria used in this review do not contradict the medical standards for proper care.

This condition is, at present, only met to a limited extent. Terminal sedation that does not have a life-shortening effect is usually regarded as normal medical practice (Van Delden 2003). But if the process can have this effect, it is often unclear whether the physician's actions should be regarded as normal medical practice or as termination of life (2003 Report). This is highly significant because there are differences in the review systems in place. Termination of life is theoretically a criminal offence, except in the case of euthanasia or assisted suicide that meets the due care criteria laid down in Article 2 of the Termination of Life on Request and Assisted Suicide Act (Articles 293 and 294 of the Criminal Code) (Legemaate 2003). Normal medical practice is excluded from criminal prosecution on the grounds of the 'medical exception'. Because it can contribute to the legitimate aims of the medical profession society entrusts it to the medical profession. The medical profession regulates this area itself on the basis of medical standards that are in accordance with general social conditions that are laid down in various texts including, among others, the Medical Treatment Agreement Act (Leenen 1996, Griffiths 1998, Leenen 2000).

As it is often unclear when terminal sedation with a life-shortening effect is normal medical practice and when it constitutes termination of life, physicians run the risk of criminal prosecution whereby their actions would be judged according to criteria that (in the physicians' view) often

leave too little room for professional judgement as to proper care. This threat probably undermines the transparency of their actions. This in turn acts as a barrier to efforts to improve the

degree of care taken when administering terminal sedation, which is in principle a normal part of responsible practice. Furthermore, this situation hampers effective control of criminal forms of terminal sedation (such as sedation that is tantamount to euthanasia, but that does not meet the due care requirements to which euthanasia is subject) because it makes it less likely that such cases will come to light.

2.2 Causes of confusion

The confusion over how to define specific instances of terminal sedation can be traced back to a problem of fact and to a conceptual issue. The problem of fact lies in determining whether the procedure had a life-shortening effect. If it did not, then the question of whether the physician's action terminated the patient's life is irrelevant. However, it is often impossible to say whether or not there was a life-terminating effect.

Sedation and suspension of artificial administration of food and fluid do not necessarily have a life-shortening effect. If carried out with due care, sedation can in fact reduce the stress on the patient and so delay, rather than hasten, the process of dying. Under these circumstances, the physician's actions are clearly in line with conventional control of pain and symptoms, and they are not controversial (Verhagen 1999, Van Delden 2003). However, withholding food and fluid will eventually always lead to death. It is therefore principally the decision to withhold food and fluid that can make terminal sedation controversial. But patients often die from their condition before the decision has a life-shortening effect. Furthermore, patients in this situation have themselves usually stopped eating and drinking prior to being sedated. Deciding to withhold artificial administration of food and fluid thus does not then change the situation to any significant degree (Ashby 1995, Dunlop 1995, Verhagen 1999, Janssens 2002, Gevers 2003a, Willems 2003, Verhagen 2004).

Though sedation and withholding of food and fluid may have a life-shortening effect, it is often very difficult to determine whether this is the case. It is often unclear whether a patient died from sedation, from his or her condition, or from a lack of food and fluid. Furthermore, it is not immediately obvious what alternative treatment should be used as a basis for comparison. In addition, it would be necessary to assess the alternative by estimating what the patient's life expectancy would have been if he or she had received that alternative treatment, something that is often hard to do (Den Hartogh 2003, Willems 2003). One point that illustrates this is that the life-shortening effect of morphine is usually overestimated (Thoms 2000, Admiraal 2001, Groenewoud 2002).

In addition to this problem of fact, defining terminal sedation often runs up against conceptual confusion as well. This is related to the fact that the demarcation line between normal medical practice with a life-shortening effect on the one hand, and termination of life on the other hand, is the subject of ethical controversy. To clarify this issue, we follow with an investigation of the

usual definitions of sedation and the withholding of artificially administered food and fluid with a life-shortening effect, and the criticisms that have arisen in response to definitions. We will then suggest an alternative that can offer greater clarity.

2.3 Sedation with a life-shortening effect

Outside the context of shortening of life, it is generally accepted that normal medical practice is one that can be justified on accepted medical grounds. This means that the intervention is carried out in response to a medical indication, with the informed consent of the patient or his or her representative, and in accordance with the principles of subsidiarity and proportionality. An exception to this is made in the case of interventions with a life-shortening effect: if a physician ‘deliberately’ and ‘actively’ brings about such an effect, then this is regarded as ‘termination of life’. This is not seen as normal medical practice.

To draw a distinction between normal medical practice with a life-shortening effect and the deliberate and active bringing about of this effect the ‘principle of double effect’ is often implicitly or explicitly used. This principle, which has its origins in moral theology, contains conditions under which an intervention that has both a morally good effect and a morally bad undesirable effect can be justified. Under that principle, someone can strive to achieve the good effect so long as his or her intention is limited to that effect and does not (also) seek to achieve the harmful undesirable effect.¹ It is important to note that the term ‘intention’ is interpreted in a restrictive manner under the principle of double effect; a person’s intention is regarded as only directed at the consequences he or she wishes to achieve. However, if someone simply foresees a particular consequence, then he or she is not regarded as having deliberately caused that consequence (Beauchamp 1994, Quill 1997b, Griffiths 1998, Keown 1999).

The principle of double effect is used in the context of shortening of life mainly to draw a distinction between conventional control of pain and symptoms with a predicted life-shortening effect and termination of life. Pain and symptom control is regarded as normal medical practice, so long as the physician’s intention does not (also) include the life-shortening effect (i.e. so long as he or she does not [also] want to bring about that effect). Termination of life is not normal medical practice because the physician indeed wants to shorten the patient’s life. The principle of double effect is used in the same way to clarify the definition of terminal sedation with a predicted life-shortening effect. So long as the physician does not administer sedation with the aim of shortening the patient’s life, his or her action can be regarded as normal medical practice. However, sedation is termination of life if the physician wants to achieve the life-shortening effect (Cherny 1998, Janssens 1999, Janssens 2001, Janssens 2002, Janssens 2003, Van Deijck 2003).

However, this argument is being exposed to increasing criticism. The principle of double effect does have a certain intuitive plausibility, being that it emphasises the physician’s intention. How-

¹ Furthermore, the action taken must not be morally harmful in itself; the harmful undesirable effect must not be caused by the beneficial effect and there must be a degree of proportionality between the beneficial effect and the harmful undesirable effect.

ever, the term 'intention' is open to multiple interpretations. Criticism is mainly levelled at the restricted meaning that is, in the principle, attached to this term. The main difficulty lies in applying the principle when classifying someone's intention on the basis of the dichotomous distinction between 'wanting' and 'merely predicting'. Three objections have been raised as a result (Searle 1980, Rachels 1986, Beauchamp 1994, Quill 1997a, Griffiths 1998, Groenewoud 2002, Gevers 2003b, Van der Wal 2003).

In the first place, doubt has been cast on the moral relevance of the distinction between wanting and merely foreseeing. If a physician acts to control pain and, alongside this, has the aim of hastening the patient's death, his or her action would be unacceptable according to this principle. However, if he or she merely expects the patient to die sooner, his or her action is acceptable even though he or she was willing to accept this consequence when deciding on what action to take. This distinction in ethical judgement is regarded as too subtle. It has been suggested instead that physicians could be held responsible for what they deliberately *or* knowingly bring about. It has also been argued that deliberately and knowingly accepting or tolerating the likelihood of an effect taking place should also be regarded as intent. This is, for example, the usual approach in criminal law.

Second, it has been stated that it often requires considerable skill to classify the physician's intention into the first or the second category. In fact, the principle of double effect does not cope well with the ambivalence that often characterises these intentions in practice. Is a physician hastening a patient's death if he or she considers that 'dying more quickly' would not be undesirable while controlling the patient's pain, or if he or she withdraws treatment in order to 'avoid prolonging life'? Such examples show that subtle differences in the formulation of an intention can be highly significant. This too can lead to arbitrary results when actions are reviewed. The principle of double effect also fails to provide physicians with any foundation on which to organise their intentions. That is because the intention with which an intervention is carried out does not in itself provide any argument as to whether or not it should be carried out.

Finally, the point has been made that intentions are difficult for third parties to appreciate. The principle of double effect is not therefore a sound foundation for public review. After all, the person monitoring the physician is largely dependent upon how the physician in question describes his or her intention.¹ It is not by chance that the criminal law allows the physician's thought processes to be deduced, where necessary, from more tangible elements, such as the means used by the physician in view of the patient's state of health.

1 As euthanasia reviews take place only after a report has been submitted by the physician, such a review also depends on the way the physician regards his or her action: he or she must, after all, 'see' it as euthanasia before reporting it. Physicians do not all view their actions in the same way (see § 2.4), far from it. This is another factor in the arbitrary nature of reviews.

2.4 Withholding of artificially administered food and fluid with a life-shortening effect

Termination of life is regarded as the deliberate and active causing of a life-shortening effect and is differentiated from normal medical practice. It has been pointed out above that there is no consensus as to how the term 'deliberate' should be defined in that context. This leads to confusion as to how sedation with a life-shortening effect should be defined. Defining the withholding of artificially administered food and fluid following sedation can also be difficult in view of the distinction between 'actively' causing a life-shortening effect and shortening life by inaction.

Outside the debate on terminal sedation, it is widely accepted that withholding the artificial administration of food and fluid is normal medical practice if starting or continuing such administration is 'medically pointless'. This remains the case if it

has a life-shortening effect. In this case as well, not carrying out an intervention that would be medically pointless is seen in moral terms as desirable rather than undesirable. Hastening the end of life by inaction is regarded as less problematic than actively shortening life. It is true that a physician has a particular duty of care towards his or her patient, and that this includes responsibility for the consequences of inaction,

but it does not apply to interventions that would be of no (further) benefit to the patient (Ashby 1995, Dunlop 1995). A person who has not received a medically pointless intervention and who subsequently dies is regarded as having died of natural causes (Leenen 2000).

This thinking can run into complications where a life is shortened as a consequence of the withholding of artificially administered food and fluid after sedation. This is particularly so where the patient became dependent on artificial feeding and hydration as a result of being sedated. As has been pointed out above, most patients who undergo sedation have themselves already stopped eating and drinking. But if a patient was still eating and drinking prior to sedation and no longer does so after being sedated, there is a clear case for saying that withholding artificial administration of food and fluid should be regarded not as a separate issue, but in connection with the previously administered sedation.¹

The presence of sedation makes the shortening of life as a result of withholding artificial administration of food and fluid, in itself an inaction, into something with an active nature. And as this means that the patient's death is in this case almost certain to occur, rather than being a theoretical possibility², this can generally be regarded as deliberate shortening of life. Looking at both decisions together, it is clear that the physician's intervention in fact amounts to termination of life (Orentlicher 1997, Quill 1997b, Orentlicher 1998, Nuy 2000).

1 The two decisions are usually taken at the same time. Investigations carried out by Van der Wal *et al.* found the decision to withhold artificial administration of food and fluid was taken at the same time as the decision to sedate the patient in 85% of cases of terminal sedation. The study further indicated that administering food or fluid was often not even considered, and that withholding it was seen as self-evident (Van der Wal 2003).

2.5 Medical-professional grounds as distinguishing criteria

If sedation and/or withholding of artificial administration of food and fluid have a life-shortening effect, then the task of deciding whether these are normal medical practice or the termination of life comes up against the problem that there is currently no satisfactory way of differentiating between termination of life (deliberately and actively shortening life) and normal medical practice with a life-shortening effect. The restrictive definition of intention in the widely-used principle of double effect creates confusion when it comes to defining sedation, as the principle often creates arbitrary outcomes. Furthermore, it is not always easy to distinguish what is and is not active shortening of life as sedation sometimes adds an active element to the shortening of life (as a result of withholding artificial administration of food and fluid).

But what is the alternative? If we reject the principle of double effect and use a broader definition of intention, then this will mean that sedation is more likely to be regarded as deliberate shortening of life and therefore, as it is active in nature, as termination of life. The related argument that sedation and the subsequent withholding of artificial administration of food and fluid must be seen in conjunction if the patient was dependent on artificial feeding and hydration prior to sedation has the same effect with regard to the second decision. This too would also be more likely to be seen as a decision to terminate life. Many of the decisions that would have to be regarded as termination of life on the basis of these arguments are, in fact, informed by good medical considerations. Taking these decisions out of the medical domain and placing them within the scope of criminal law would be unsatisfactory.

There is an alternative way of defining terminal sedation that is more satisfactory, as it makes it more clear to physicians where the dividing line between normal medical practice and termination of life lies and does not unnecessarily bring their actions within the remit of the criminal law. This alternative takes the criterion that is generally used to define normal medical practice in contexts other than the shortening of life (the existence of accepted medical grounds) and applies it in that context as well. In this case, interventions that can be justified on medical grounds are *always* regarded as normal medical practice, even if they actively bring about a life-shortening effect and irrespective of whether the physician tolerates, welcomes or desires that effect. The existence of medical grounds takes precedence over the significance of that latter aspect in defining a physician's intervention (Beauchamp 1994, Griffiths 1998, Harris 1999, Gevers 2003b).

Under this alternative, we would regard termination of life only as situations in which the physician deliberately and actively caused a life-shortening effect by means of an intervention that could not be justified on the basis of accepted medical grounds. 'Deliberate' would include a situation in which a physician foresaw and tolerated the life-shortening effect or accepted the likelihood of such an effect taking place. This is the case with euthanasia, for example. Euthanasia is

2 As has been stated, it is not certain that the patient will die as a result of the physician's decision – the patient might die from his or her disease – but it is certain that withholding artificial administration of food and fluid could shorten the patient's life: if the patient does not die from his or her disease, he or she will die from a lack of food and fluid. This is distinct from conventional pain control.

an intervention that, in view of the means employed, can only be regarded as having death as its objective. This action cannot be justified on medical grounds. For that reason, euthanasia is not normal medical practice and 'unbearable and hopeless suffering' is regarded as a necessary precondition, but not a medical indication, for euthanasia (Leenen 1996).

This type of distinction leads to a situation where sedation can be regarded as normal medical practice if it is carried out in response to a medical indication, with the informed consent of the patient or his or her representative, and in accordance with the principles of subsidiarity and proportionality. Withholding artificial administration of food and fluid after such sedation is a normal medical practice if starting or continuing such administration would be medically pointless or if the patient or his or her representative asks the physician to withhold food and fluid.

Drawing a distinction between normal medical practice with a life-shortening effect and termination of life on the basis of accepted medical grounds offers physicians more clarity as to the review system that would apply to their action. Terminal sedation and the withholding of artificial administration of food and fluid that can be justified on medical grounds then fall under the medical exemption and can be reviewed by the medical profession itself on the basis of professional medical norms. This offers physicians the certainty that reviews will use criteria that are regarded as suitable within their profession. This will make their actions more transparent and more open to review, further increasing opportunities to monitor the degree of care with which they are carried out and, if necessary, to improve it.

A further advantage of this approach is that it makes it easier to control the grounds on which physicians can justify their actions to third parties. They no longer take the form of subtle formulations of intent, but are related to the patient's state of health and accepted medical opinion as to the proper course of action. The worse a patient's condition and the shorter his or her life expectancy, the easier it will be, for example, for a physician to justify his or her intervention on medical-professional grounds. This also makes a physician's intervention more open to review.

It will not always be completely obvious whether certain symptoms can be taken as a medical indication for terminal sedation. That will sometimes be a matter for discussion. However, it will always be possible to hold such discussions on the basis of professional considerations, which can only serve to clarify the situation.

Where it is not possible to justify a decision to sedate a patient and/or withhold artificial administration of food and fluid on accepted medical-professional grounds, then this situation cannot be regarded as normal medical practice. Three possible scenarios can be considered if the intervention has a life-shortening effect, and it will not always be easy to distinguish between them in practice. The physician's intervention is theoretically liable to criminal prosecution in all these scenarios.

(i) Shortening of life that is the predicted and at least tolerated consequence of the administration of sedatives without a medical indication is termination of life. If this is done at the patient's request, then it is euthanasia. As sedatives are not suitable for euthanasia, this procedure does not meet the requirements of due care laid down in Article 2 of the Termination of Life Review Procedures Act and is therefore liable to criminal prosecution. This may go some way towards explaining why euthanasia carried out by terminal sedation is never reported, as is also the case for euthanasia carried out by the administration of morphine (Den Hartogh 2003).¹ If life is terminated when the patient is in a terminal phase, this can also be what the Rummelink committee referred to as 'help in dying': giving a little push at the time that vital functions start to fail (Rummelink Committee 1991). This is also clearly not regarded as normal medical practice (Leenen 2000, Leenen 2001).

(ii) If there was no medical indication for sedation, but it is carried out, for example, purely at the patient's request, and if death is hastened as a consequence of the withholding of food and fluid at the request of the patient (or his or her representative), then the circumstances surrounding the death and the physician's actions are at least controversial. That is because there was no medical indication for sedation and any request by the patient cannot of itself justify sedation. If the patient had become dependent on artificial administration of food and fluid prior to sedation, then the related argument can be put forward to describe this action as termination of life. If the request is made by a mentally competent patient, then this is related to euthanasia.

(iii) In a situation where there was no medical indication for sedation, and withholding artificial administration of food or fluid (without request or because it is medically pointless) would accelerate death, then the circumstances surrounding the death and the physician's actions are also at least controversial. If the patient had become dependent on artificial administration of food and fluid as a result of sedation, then here again this can be described as termination of life.

3 Proper care

3.1 Principles

Terminal sedation and withholding artificial administration of food and fluid can, as has been shown above, be defined as normal medical practice if it can be justified on accepted medical-professional grounds. However, the issue of when terminal sedation also constitutes proper care is a matter that has not yet been clearly resolved. The terms of the debate, which needs to be conducted primarily within the medical profession, have not yet crystallised. However, some principles relating to proper care can be deduced from the general conditions for normal medical practice (medical indication, informed consent, subsidiarity and proportionality) and from the ethics of palliative and terminal care. We will explain and examine these below.

¹ Another aspect of this explanation may be that physicians do not 'see' intervention of this kind as euthanasia; see § 2.4.

The ethics of palliative and terminal care can give rise to a medical-professional responsibility on the physician to help the patient achieve a 'good death'. Terminal sedation is an extreme form of palliation that is considered when other palliative options have been exhausted. Palliative care is not directed at healing, but has the aim of making the patient's suffering caused by the disease as bearable and manageable as possible (WHO 2002). Palliative care becomes terminal care once it becomes impossible to heal the patient or restore a function, and the patient is close to death (Ashby 1995). In this phase, the physician's prime concern is care rather than cure, and this is achieved by maximising the patient's comfort. Maintaining life is of lesser importance under these conditions (Cherny 1998).

Terminal sedation can contribute to a good death by removing pain, anxiety and confusion and by allowing the process of dying to take place in a calm and dignified manner. However, a number of aspects that are regarded in the West as important elements of a good death are put under pressure in the case of terminal sedation: awareness of death, a feeling of direction and control, and the convergence of the end of life in a biological, spiritual and social sense. The degree of consciousness often gradually declines as death approaches. Under these circumstances, control falls into the physician's hands. And once a patient has completely lost consciousness, his or her relatives may have to wait for several days until death actually occurs (Lawton 2000, Smith 2000, Janssens 2003, Deliens 2003, Van Deijck 2003, Willems 2003). The situation with these issues differs from euthanasia. Patients undergoing euthanasia may feel more in control and saying goodbye to relatives may be more bearable for both the patient and the relatives (Swarte 2003b).

Physicians have a more clear-cut responsibility for the quality of death in the case of normal medical practice than in the case of euthanasia. Nevertheless, a good death in a medical setting is still thought of mainly in terms of euthanasia. Furthermore, considerations as to the role and responsibility of physicians in bringing about a good death are limited principally to biomedical aspects and are nearly always formulated in terms of medical interventions. A broader perspective is desirable in this respect as well (Payne 1996, Janssens 2001, Willems 2003). Terminal care should not be restricted to biological aspects, but must also reflect existential, emotional and social concerns (Emanuel 1998a, Emanuel 1998b, Callahan 2000, WHO 2002).

There is surprisingly little empirical data on the quality of dying in current medical surroundings. Anecdotal evidence leads us to suspect that the expectations and wishes that people have about their own death, and the expectations and wishes of their relatives, are usually not met (Nuland 1993, Smith 2000). It is more likely than not that individuals in a terminal phase experience physical pain, feelings of disintegration and abandonment, and associated depressive symptoms (Emanuel 1998a, Swarte 2003a). These symptoms increase the tragedy that death already represents for all concerned (the patient, his or her relatives, physicians and nurses) and may be traumatic to those who are closest to the patient. More consideration should be given to these aspects.

The following principles can be derived from the conditions for normal medical practice and the ethics of palliative and terminal care, and can be applied to proper care in the context of terminal sedation.

3.2 Medical indication, subsidiarity and proportionality

The question of whether terminal sedation is indicated depends on the patient's state of health. The symptoms that can indicate that sedation is required are called refractory symptoms. They are common, with comparative studies showing that 16-52% of terminal cancer patients experience refractory symptoms in the last few days prior to death, and similar percentages have been observed for other categories. These are mainly severe forms of pain, nausea and vomiting, tightness of the chest and delirium. But non-physical factors such as agitation, fear and a feeling of abandonment can also contribute to suffering that cannot be relieved by conventional means (Lichter 1990, Ventafriida 1990, Fainsinger 1991, Chater 1998, Cherny 1998, Willems 2003, Verhagen 2004).

Sedation must comply with the principles of subsidiarity and proportionality, as well as the requirement for a medical indication. The subsidiarity principle states that physicians must select the intervention that causes least discomfort to the patient when choosing among all interventions that may be effective. The proportionality principle requires that any discomfort caused by the intervention must be justified by the goal that is to be achieved. These principles therefore require physicians to estimate and weigh up the advantages and disadvantages of sedation. Sedation can be indicated on these grounds if it is clear that the patient's refractory symptoms are unavoidable and that less invasive forms of palliation have failed (Burke 1991, Cherny 1998, De Graeff 2002, Van Deijck 2003). This will usually, but not necessarily, be the case in the terminal phase. Sedation is also ineffective against some clinical symptoms such as bleeding, faecal vomiting and refractory diarrhoea. The patient will be unaware of these symptoms, but they can come as a shock to his or her loved ones (Quill 1997b).

An adequate depth, or lightness, of sedation is an important aspect. It must be sufficiently deep to control the refractory symptoms as far as possible, but it should not be deeper than necessary because loss of consciousness is not of itself desirable. It is sometimes enough to put the patient in a light sleep. Light sedation can also be an option at a later stage if the patient wants to have contact with his or her family (Verhagen 1999, Verhagen 2004). But this can be extremely distressing for the patient and his or her family if the refractory symptoms return. A firm approach is sometimes needed to deal with terminal sedation in order to prevent the patient unintentionally regaining consciousness (Dunlop 1995, Emanuel 1998). Sedation is therefore a process that must be continually assessed by the physician.

The artificial administration of food and fluid must also meet the requirements of subsidiarity and proportionality. If not, then this process should not be started or continued. Sedation itself may not justify regarding artificial administration of food and fluid as medically pointless (Gevers 2003b). But when deep sedation is decided on for good reasons, artificial administration of food and

fluid is usually not indicated. Under these circumstances, any action that prolongs life is in fact an action that only prolongs death. That cannot be regarded as beneficial at this stage (Jacobs 1991, Dupuis 1994, Verweij 1999, Verhagen 2004). Furthermore, the artificial administration of food and fluid can cause iatrogenic damage in the form of increased oedema, bronchial secretion, dyspnoea, increased urine output and incontinence. Such action can therefore be disproportionate (Ashby 1995, Janssens 2002). However, artificial administration of food and fluid is still desirable if the patient or his or her relatives need to reduce sedation for a short time to say goodbye to each other.

Though it is in principle up to the patient or his or her representative to decide whether an intervention can, in a proportional manner, achieve goals that benefit the patient, the physician must also form a judgement on this point. This is essential so that the physician can give the patient sound information. Furthermore, the physician must decide whether further intervention is pointless because it can no longer serve any useful purpose.

3.3 Autonomy of and communication with the patient

Proper care is characterised by respect for the patient's autonomy. This also applies to terminal sedation and the withholding of artificial administration of food and fluid. In principle, a physician must have the patient's informed consent to administer terminal sedation (Article 7:450 of the civil code). This requirement is designed to ensure the autonomy of mentally competent patients. However, it will not always be possible in acute situations to ask for consent, and consent can be assumed for simple actions (Article 7:466 of the civil code). However, terminal sedation cannot, in principle, be described as a simple action. If the patient is mentally incompetent, then the consent of his or her representative is required (Article 7:465 of the civil code).

Respect for autonomy depends on good communication with the patient. Opinions as to what constitutes a good death can vary considerably between physicians and patients, and between different patients (Payne 1996, Willems 2003). The values of the individual patient must be the deciding factor. Once it becomes clear that the patient is close to death and offering comfort takes precedence, the physician must find out what the patient regards as a good death and what impediments stand in the way of achieving this. This should be done by talking to the patient, with both parties deciding on what care tasks remain. The physician will give the patient a prognosis and judges whether refractory symptoms might occur. He or she will also clearly set out the various advantages and disadvantages of the remaining options, including terminal sedation and withholding artificial administration of food and fluid. It can sometimes be useful to inform patients with refractory symptoms of their option to choose between euthanasia and waiting for a situation to arise in which terminal sedation may be indicated (Emanuel 1998b). When coming to a decision as to sedation, physicians are also advised to point out that the patient will probably not receive food or fluid after sedation has been administered.

It is important to bear in mind that communication can often break down in the terminal phase, and that the patient's state of health can change rapidly. For those reasons, autonomy is mostly an illusion in the last few moments. This is exactly why it is so important for the physician and patient to build up a trusting relationship, for the patient to be prepared for what may come and to tell the physician in good time what he or she would like to happen. In this way, the physician and patient will not be confronted with a situation in which the patient can no longer participate in decisions (Cherny 1998, Emanuel 1998b, De Graeff 2002, Janssens 2002, Verhagen 2004).

A living will can help patients to retain autonomy, even in the terminal phase. This is particularly so where a patient does not want treatment. In a living will, a patient states, for example, that in the event of subsequent loss of mental competence he or she does not want to receive artificial administration of food or fluid under a particular set of circumstances. These documents are, theoretically, legally binding on physicians and on patients' representatives (Article 7:450 clause 3 of the civil code). Treatment requests, where a patient states beforehand that he or she would like to receive a particular form of treatment under certain circumstances, have a much weaker status and are not legally binding. They place no obligation on the physician and do not authorise him or her to carry out pointless treatments. Written requests for euthanasia have a somewhat different position. They may authorise – but not oblige – a physician to take action to terminate life (Article 2 clause 2 of the Termination of Life on Request and Assisted Suicide Act) (Biesart 2003). A (positive) request for sedation may, combined with a refusal of treatment, play a similar role as a request for euthanasia.

3.4 Relatives

Dying is also a social process (Ariès 1994, Payne 1996, Chabot 2001). A good death is often predicated on specific forms of social interaction. If it is important to the patient to die as he or she has lived, then his or her social values will help shape his or her expectations as to what constitutes a good death. More specifically, support from family and friends and being able to say goodbye properly can be very precious to the patient. A physician who is providing due care will take account of this.

The involvement of family members can also be important in the dying process from another point of view. The patient will often eventually lose his or her ability to communicate his or her wishes and needs to the physician, and will no longer be able to participate in decisions. If the patient has not made a living will, then relatives will be able to inform the physician and, where necessary, help him or her reconstitute the patient's wishes (for example in deciding whether it still makes sense to carry out a particular treatment). The physician must keep relatives well informed in this situation (Janssens 1999, Verhagen 1999, Verweij 1999, De Graeff 2002). It is important to ensure that all the patient's rights are upheld with this. For instance, if the patient has indicated that he or she does not want his or her relatives to be involved in decisions, then this must be respected.

Finally, we come to the position of the family itself. A physician's duty of care extends to a patient's relatives, both before and after death (WHO 2002). Good communication and support can be of great significance in determining how the family experiences the dying process and how they cope with their relative's death. One of the physician's tasks is to demolish unrealistic expectations. He or she might prepare the relatives for the 'improvisation' that the uncertainties surrounding the dying process impose, and tell them that he or she might have to choose between conflicting goals. For example, it is not always possible to keep the patient both conscious and pain-free. Another important factor is that having the opportunity to say goodbye to the patient has a beneficial effect on the relatives' grieving process (Craig 1994, Wilkes 1994, Ashby 1995, Swarte 2003b).

3.5 Consultation

Even when the patient's state of health is a good reason to administer terminal sedation and to withhold artificial administration of food and fluid, these are still major decisions. In order to assess whether a medical indication is present and whether the principles of subsidiarity and proportionality are met, it is advisable for the physician to consult a colleague who is an expert in recognising physical and non-physical refractory symptoms, palliative treatment options and sedation. This provides an additional assurance in coming to carefully considered decisions (Quill 1997b, Cherny 1998, Emanuel 1998b, De Graeff 2002, Verhagen 2004).

3.6 The medico-technical aspects of due care

The selection and administration of the sedative is the main point to consider in the medico-technical aspects of due care.

Benzodiazepines, such as midazolam and diazepam, are usually the most suitable substances for sedation. They are effective and cause few undesirable effects. Midazolam does not necessarily cause loss of consciousness, but almost always suppresses terminal agitation and allows the patient to sleep. Benzodiazepines are preferably administered subcutaneously, or otherwise through rectal or intravenous administration. Dosage depends principally on the symptoms, which can fluctuate markedly (Burke 1991, Chater 1998, Cherny 1998, De Graeff 2002, Swart 2003, Verhagen 2004).

Where a patient is receiving morphine and sedation is indicated, the obvious route might seem to be to gradually increase the morphine dose. However, opioids are not really suitable for sedation, especially in patients who have developed a tolerance. Morphine is not certain to produce sedation and often has unpredictable undesirable effects (such as delirium). However, as benzodiazepines do not have a painkilling effect, a combination of benzodiazepine and morphine may indeed be indicated (Burke 1991, Cherny 1998, Verhagen 1999, De Graeff 2002, Verhagen 2004).

3.7 Reporting

The need for transparency and verifiability implies that a physician providing due care should indicate in the patient's medical records what the reasons for his or her decisions were, how far the patient and his or her relatives were involved in the decision, what experts he or she consulted, and what substances were administered, at what doses and via what route.

4 Clinical practice

Terminal sedation is surrounded by various uncertainties. These include uncertainty as to how the process can be made more transparent and open to review, the requirements of due care as applied to terminal sedation, and, finally, aspects of clinical practice in the context of terminal sedation. In their most recent assessment of the review procedure relating to euthanasia, Van der Wal *et al* looked for the first time at the practice of terminal sedation (Van der Wal 2003). Partly because this was not actually the primary focus of their work, their findings do not give a clear picture of this practice. It is particularly unclear to what extent terminal sedation that is performed meets the requirements for normal medical practice and can be regarded as proper care.

4.1 Frequency and classification

Van der Wal *et al* carried out a number of activities as part of their assessment, including a mortality review and interviews with physicians. The mortality review was limited to 'medical decisions concerning the end of life' (MDELs). These are decisions where the physician took account of, or intended to bring about, acceleration of the end of life. Interviews with physicians also looked at cases where life may have been shortened and where the physician neither sought to accelerate the end of life nor took it into account.

The review found that the patient underwent deep sedation prior to death in 6% (mortality review) and 12.2% (interviews with physicians) of the deaths investigated. The mortality review showed that the decision to administer sedation and withhold all artificial administration of food and fluid had been taken in 3.9% of deaths. The interviews with physicians revealed that it had been decided to sedate the patient before death and to withhold artificial administration of quantities of food and fluid needed to sustain life in 10% of the deaths. Terminal sedation is therefore a relatively common practice, compared to euthanasia (2.4% of all deaths). The limited amount of literature available indicates that the prevalence of this practice may be similar or higher in other countries (Stone 1997, Fainsinger 2000, Janssens 2001, Janssens 2003).

Van der Wal *et al* took the cases of terminal sedation associated with withholding of artificial administration of food and fluid that they found in their mortality review and classified into their MDEL categories. These MDELs are classified as euthanasia, assisted suicide, termination of life without request, intensive pain and symptom control that may have a life-shortening effect, and the decision not to initiate (or to withdraw) a potentially life-prolonging treatment. Van der Wal

et al found that approximately 48% of the cases of terminal sedation under consideration could be described as intensive pain and symptom control. Patients had been given substances with the express aim of hastening their death in around 15% of cases. This was usually done at the patient's request, and these cases can, in the opinion of Van der Wal *et al*, be regarded as euthanasia.¹

They classified the other 38% of decisions as 'decisions to stop or refrain from treatment'.

The most commonly cited reasons for sedation were pain (54%), agitation (43%), tightness of the chest (30%) and anxiety (12%) suffered by the patient. The extent to which life had been shortened was estimated at one week or less in 51% of cases, one to four weeks in 21% of cases and one to six months in 3% of cases. In 23% of cases, the decisions were not regarded as having shortened the patient's life. Cancer was the most frequent (66%) diagnosis for patients undergoing terminal sedation.

Comments

Two comments can be made regarding the use of this MDEL classification in describing actions with a life-shortening effect. The first is that it can be difficult to objectively record a physician's intention relating to a particular intervention. As intention is a key criterion in classifying MDELs, this leads to uncertainty as to the frequency of the various MDELs. Second, this MDEL classification does not fit well with the definition of normal medical practice. This means that even if the frequency of MDELs were clearly established, it would still not be clear how far interventions with a life-shortening effect can be classified as normal medical practice.

(1) RECORDING INTENTIONS

The MDEL classification categorises interventions with a life-shortening effect on the basis of various criteria, including, among others, the intention with which they were carried out. This applies in particular to drawing a distinction between intensive pain and symptom control with a potentially life-shortening effect on the one hand and euthanasia and termination of life without request on the other hand. Three possible intentions are used to draw this distinction. In the case of intensive pain and symptom control, a physician administers substances 'bearing in mind the probability or certainty' that they will hasten death, or 'partly with the aim' of hastening death. In the case of euthanasia and termination of life without request, he or she administers substances 'with the express aim' of hastening the patient's death.

It is well known that intentions relating to end-of-life decisions are, in practice, often shrouded in ambivalence and ambiguity (Quill 1993, Quill 1996). We have stated in § 2.2 that this can cause problems when applying the principle of double effect. But it also raises difficulties for empirical research such as that conducted by Van der Wal *et al*, where conclusions as to the frequency of various MDELs are based on physicians' reports. Participative studies have in fact shown that physicians often perceive and describe their intentions and actions in an individual, highly personal way

¹ These cases may have been only attempted euthanasia, as sedation does not always shorten life.

in situations involving the shortening of life (Benjaminsen 1988, Melief 1991, Pool 1996, Pool 1998, Van Tol 2001). These descriptions can vary from physician to physician, and also often fail to match the concepts underlying the MDEL classification. If a physician is asked to answer a question as to the intention with which he carried out a particular action, or about a particular action that is characterised largely by an intention, in terms that are not his or her own, then the answer is the product of a reconstruction. This reconstruction can be particularly tricky as the dividing lines between MDELs are sometimes flimsy. For instance, the distinction between 'with the express aim' and 'partly with the aim' is quite subtle. This increases the likelihood of individual factors determining the MDEL category in which an instance of a life-shortening intervention is placed (Quill 1996, Den Hartogh 2003).

There are reasons to consider that the way in which physicians perceive and describe their own intentions and actions is sometimes partly dependent upon their moral views. For instance, some physicians do not 'see' an intervention that is actually euthanasia as such if they think the patient's request is fully justified by his or her state of health and life expectancy (Pool 1996, Pool 1998). As physicians practice medicine with a view to the patient's life rather than his or her death, it is not really surprising that in cases such as these a physician would regard relieving suffering as his or her prime intention, and would not see hastening the patient's death as his or her express goal. This is why shortening of life would not then be reported as euthanasia.¹

This difficulty confronting the recording of physicians' intentions explains why there are inevitably 'grey areas' between the cases of euthanasia and termination of life without request, on the one hand, and intensive pain and symptom control with a potentially life-shortening effect, on the other hand. This borderline area is characterised by lack of clarity as to the number of cases involved and as to how the decisions in question should be qualified (as euthanasia or termination of life without request, or as intensive pain and symptom control) (Griffiths 1998).

Van der Wal *et al* recognise that these grey areas exist. They point to cases where a physician reported having stepped up pain and symptom control with the express aim of hastening death, and to cases where a physician reported having acted in a manner that terminated life without the patient's express request, but stated that he or she did not have the express aim of hastening death. All these cases were classified as instances of intensive pain and symptom control. Their prevalence is estimated at 1.4% and 0.3% of the total number of deaths, respectively. These are relatively high percentages compared to the 'official' statistics for euthanasia (2.4%) and termination of life without request (0.7%). However, this estimate does not take account of

1 Compare the finding in the context of the second review of the reporting procedure and the practice of euthanasia that 'many physicians had difficulty with the term with the express aim of hastening death because throughout the practice of their profession they were always focusing on the patient's life and not on his or her death' (De Graaff 1996). And in the context of the same research, the explanation put forward by Van der Wal and Van der Maas for the relative increase in euthanasia between 1991 and 1995: '[it] seems ... that respondents now attribute a 'darker' intention to cases of stepping up pain and/or symptom control' (Van der Wal 1996). This indicates that physicians sometimes want to avoid describing their own actions as euthanasia or termination of life. This can also be an important explanation for the reporting percentages of euthanasia. Failure to report would then not necessarily be due to bad faith, as is sometimes thought (Den Hartogh 2003). It is also not true to say that the way physicians conceptualise this issue is of itself less 'good' than the way the investigators regard it.

the possibility that the thoughts and wishes of the physician at the time that the life-shortening action was taken might not mesh with the conceptual framework of the investigators, and was reported to them in such a way that if they had been able to see the case for themselves they would have reconstructed it in the wrong way.

This may, for example, be the case in the situation referred to above: a physician is in fact performing euthanasia but describes his or her prime intention as relieving the patient's suffering and so does not regard the intervention as euthanasia. Consequently, we do not know how large this grey area is or the frequency of such MDELs (Griffiths 1998).

This problem particularly affects the classification of terminal sedation and the associated withholding of artificial administration of food and fluid, as this combination lies at the boundaries of various MDEL categories. For example, there are grey areas between euthanasia or termination of life without request by means of terminal sedation, on the one hand, and terminal sedation in the form of intensive pain and symptom control, on the other hand. Furthermore, differences in reported intentions have played an important role in the choice as to whether terminal sedation is placed in the 'intensive pain and symptom control' category or in the 'decision not to treat' category. For example, where a physician considers that the decision to sedate the patient was taken without the express aim of hastening the patient's death, but that the decision to withhold artificial administration of food and fluid was taken with that aim, the case is classified as a decision not to treat. If the same intention is reported for both decisions, then the case is classified in the 'intensive pain and symptom control' category.¹ Here again, the existence of a grey area can be assumed.

These grey areas mean that the classification of terminal sedation by Van der Wal *et al* is shrouded in uncertainty.

(II) MDELS AND NORMAL MEDICAL PRACTICE

The second comment on the use of the MDEL classification is that it does not fit in with the definition of normal medical practice with a life-shortening effect. That is particularly true for the definition put forward in the preceding section.

This comment can be illustrated on the basis of the MDEL category of 'intensive pain and symptom control with a potentially life-shortening effect', in which half of the cases of terminal sedation examined were classified. As has been indicated, this category is distinguished from the categories of euthanasia and action to terminate life without request on the basis of the physician's intention. However, it has been pointed out in § 2.2 that the subtle characteristics of the physician's intention also do not form a good basis for answering the question of whether his or her action should be regarded as a normal medical practice, if that action may have a life-shortening effect. If the physician predicts and knowingly tolerates a possible life-shortening effect, then the question of whether he or she also wants to achieve this effect is less morally relevant.²

¹ Report by Dr. A van der Heide, Erasmus MC.

What is more important is to determine whether there are good medical grounds for his or her action.

A similar remark can be made on the 'decision not to treat' category. These decisions are taken when a physician decides not to start, or to stop, a potentially life-prolonging treatment. This is not necessarily a normal medical practice. As a result, there is a requirement that starting or continuing a treatment would be medically pointless, or that the patient has asked for the treatment not to be started (or to be stopped).

Classifying terminal sedation within the MDEL categories therefore leaves some uncertainty as to how far it can be regarded as normal medical practice (for example, in terms of the definition of normal medical practice as action that can be justified on medical grounds).

These two comments are not intended to dismiss the MDEL classification, but to express some reservations with regard to it. They highlight the need for further investigation, looking less at subtle variations in intention as the criterion for classification and instead focusing on factors that are of importance from the point of view of the medical profession (such as the grounds on which, and the circumstances under which, the decision to sedate is taken, and the substances and doses used) (Chater 1998, Admiraal 2001).

4.2 Due care

As well as knowing how often and in what form terminal sedation takes place, it is also important to know to what extent it is carried out with due care. Van der Wal *et al* considered various aspects of acting with due care in their investigation. Their main findings can be summarised as follows:

- The patient was not involved in the decision in 43% of cases of terminal sedation, usually because it was difficult to communicate with him or her. The decision to withhold artificial administration of food and fluid was not discussed with the patient in 69% of cases, often because it was difficult to communicate with him or her, or because the decision was regarded as self-evident. Similar percentages have been observed in other countries (Chater 1998).
- The decision to sedate was discussed with the patient's relatives in 92% of cases. The decision to withhold artificial administration of food and fluid was discussed with the relatives by nursing home physicians in 91% of cases, and by GPs and specialists in 66% of the cases. Similar percentages have also been observed for this situation in other countries (Chater 1998). When the patient was not consulted with regard to sedation, his or her relatives were indeed

2 For those who wish to hold on to the principle of double effect, it is important to note that there is a discrepancy between the 'intensive pain and symptom control' category as defined by Van der Wal *et al* and as defined on the basis of that principle. According to that principle, action taken 'partly with the aim' of hastening death is not palliative, but life terminating, action.

consulted in 89% of cases. The corresponding figure for withholding of artificial administration of food and fluid is 59%.¹

- Specialists consulted colleagues with regard to sedation in 76% of cases, while the corresponding figures for nursing home physicians and GPs are 38% and 29%, respectively. Experts in the field of palliative care were involved in the decision in only 11% of cases.
- Morphine alone was used in 27% of the investigated cases of terminal sedation. These findings show that the degree of care with which terminal sedation is carried out leaves room for improvement. However, they cover only a small number of aspects of due care. Although they are very important, they cannot form a sufficient basis for firm conclusions. Further research is needed here as well.

5 Implications for public policy

One of the factors stimulating the debate on terminal sedation in the Netherlands is, as indicated here, concern as to the degree of care with which it is administered. This concern is understandable. After all, sedating a patient and then withholding artificial administration of food and fluid markedly reduces his or her level of consciousness prior to death, and may also shorten his or her life. Even if terminal sedation is the ultimate remedy when it comes to relieving the patient's suffering, these are major decisions. It is important that physicians respect fundamental values and norms when taking these decisions, and that they act with the greatest care. The risk that this may not be the case is at least comparable to the risk associated with euthanasia. This is because terminal sedation is, after all, usually administered to people who are approaching death and who are especially vulnerable. It is not impossible that a physician may fail to inform the patient properly, act without his or her consent, or against his or her wishes. This is particularly true of the withholding of artificial administration of food and fluid after sedation, as the physician now has full control of the situation (Quill 1996, Orentlicher 1997, Quill 1997b, Orentlicher 1998, Van Deijck 2003).

Though the research carried out by Van der Wal *et al* provides no indication that there is a serious lack of care in the administration of terminal sedation in practice, the findings should prompt us to consider how the care with which terminal sedation is performed can be better monitored and improved. Their study shows that terminal sedation is quite a common practice and that the degree of care with which it is carried out could be improved. In many cases, the patient's autonomy is not sufficiently assured because the decision is taken at a time when it is no longer possible to communicate with the patient. Failure to recognise refractory symptoms in time may have something to do with this, and that in turn may be connected to the fact that physicians do not normally consult experts in palliative care. Additionally, nursing home physicians and GPs do not in most cases consult colleagues when deciding whether to administer terminal sedation. Finally, morphine alone (a substance that is not appropriate for sedation) is used in over a quarter of cases.

1 Report by Dr. A van der Heide, Erasmus MC.

Transparency and verifiability are the primary conditions for monitoring and improving the degree of care with which terminal sedation is carried out. These in turn depend on the clarity of the review system in place, and on having a clear answer to the question of when terminal sedation is normal medical practice and when it constitutes termination of life. We have pointed out that the subtle characteristics of the physician's intentions do not provide a good basis for this. We therefore recommend that normal medical practice with a life-shortening effect should no longer be defined on the basis of the physician's intentions, but, as is usual in cases where interventions do not shorten life, should be defined on the basis of accepted medical grounds (medical indication, informed consent, subsidiarity and proportionality).

This definition would regard action as termination of life only if the physician deliberately and actively brought about a life-shortening effect by means of an intervention that could not be justified on accepted medical grounds ('deliberately' would be considered as foreseeing and tolerating the life-shortening effect, or accepting the likelihood that such an effect would occur). This is the case with, for example, euthanasia. Euthanasia is an intervention that, in view of the means employed, can only be regarded as having death as its objective. This action cannot be justified on professional medical grounds. This is why euthanasia is not normal medical practice and the requirement of 'unbearable and hopeless suffering' is not regarded as a medical indication for euthanasia.

Classifying physicians' actions in this way offers them more certainty that terminal sedation, where appropriate, will be judged on the grounds of medical standards of due care rather than by the criteria of criminal law. Terminal sedation that can be justified on accepted medical grounds then falls under the medical exemption. Such cases are reviewed exclusively by the medical profession.¹ How this professional review process can be improved is an important question that deserves particular attention.

Terminal sedation that cannot be justified on accepted medical grounds (for example, because the patient has no refractory symptoms) can and must remain a criminal offence. A clearer understanding of when terminal sedation is not a criminal offence will help improve the effectiveness of controls over forms that are indeed a criminal offence.

Clarity as to how terminal sedation is classified should have a beneficial effect on physicians' willingness to accept transparency. It is vital to make use of the opportunities this offers to improve, where necessary, the degree of care they exercise. That depends on the medical profession taking an active position. It is desirable that the medical profession conduct a more intensive debate as to when terminal sedation constitutes proper care and that they should draw up authoritative guidelines (Gevers 2003a, Gevers 2003b, Van Deijck 2003).² This should, among other things,

1 Compare the 1985 proposal of the State Euthanasia Commission to exempt from criminal law 'hastening of death as an incidental consequence of a treatment that is necessary for, and by its nature directly designed to, relieve a patient's extreme suffering' (Den Hartogh 2003).

2 Some guidelines for terminal sedation have already been devised abroad and in certain parts of the Netherlands (De Graeff 2002, Verhagen 2004).

create more clarity as to the symptoms that can serve as a medical indication for terminal sedation and as to the circumstances under which artificial administration of food and fluid is pointless. Investment in developing expertise is also important. The government can act to stimulate and facilitate all these developments.

Further research is needed to obtain a better understanding of how terminal sedation is administered in clinical practice and to better assess what policy initiatives would be beneficial. We do not as yet have a clear picture of this practice. The context of this additional research should focus less on the specific characteristics of physicians' intentions and should concentrate instead on factors that are important from the point of view of the medical profession.¹

¹ See Reuzel 2002 and Deliens 2003 for current investigations of terminal sedation and palliative care.

Bibliography

- Admiraal P, Griffiths J. Sterven aan pijnbestrijding. Medisch contact 2001; 56: 463-466
- Ariès P. Western attitudes toward death: from the Middle Ages to the present. London: Marion Boyars, 1994
- Ashby M, Stoffell B. Artificial hydration and alimentation at the end of life: a reply to Craig. Journal of medical ethics 1995; 21: 135-150
- Beauchamp TL, Childress JF. Principles of biomedical ethics. Fifth edition. New York: Oxford University Press, 2001
- Benjaminsen M. Bij het einde. Een onderzoek naar terminale zorg en euthanasieproblematiek in Utrecht. Utrecht: Gemeente Utrecht, 1988
- Biesart MCIH. De schriftelijke wilsverklaring. In: Legemaate J, Dillmann RJM (red.). Levensbeëindigend handelen door een arts op verzoek van de patiënt. Houten: Bohn Stafleu Van Loghum, 2003; 118-133
- Burke AL, Diamond PL, Hulbert J ea. Terminal restlessness - its management and the role of midazolam. The medical journal of Australia 1991; 155: 485-487
- Callahan D. The troubled dream of life. Washington DC: Georgetown University Press, 2000
- Chabot BE. Sterfwerk. De dramaturgie van zelfdoding in eigen kring. Nijmegen: Sun, 2001
- Chater S, Viola R, Paterson J ea. Sedation for intractable distress in the dying - a survey of experts. Palliative medicine 1998; 12: 255-269
- Cherny NI, Portenoy RK. Sedation in the management of refractory symptoms: guidelines for evaluation and treatment. Journal of palliative care 1994; 10: 31-38
- Commissie Rimmelink. Medische beslissingen rond het levenseinde. Den Haag: SDU, 1991
- Craig GM. On withholding nutrition and hydration in the terminally ill: has palliative medicine gone too far? Journal of medical ethics 1994; 20: 139-143
- De Graeff C, Kester J. Het levenseinde in de medische praktijk (1995, 1990). Resultaten sterfgevallenonderzoek 1995, deelonderzoek II van het evaluatieonderzoek Meldingsprocedure euthanasie. Voorburg: CBS, 1996
- De Graeff A, Verhagen EH, Eliel MR ea (red.). Oncologieboek IKMN 2002. Deel II: Richtlijnen palliatieve zorg. Utrecht: Integraal Kankercentrum Midden Nederland, 2002
- Deliens L, Van Bokhoven RFM, Van der Wal G. De relatie tussen palliatieve zorg en medische beslissingen rond het levenseinde: feiten en ontwikkelingen. In: Legemaate J, Dillmann RJM (red.). Levensbeëindigend handelen door een arts op verzoek van de patiënt. Houten: Bohn Stafleu Van Loghum, 2003; 180-190
- Den Hartogh G. Mysterieuze cijfers. Medisch contact 2003; 58: 1063-1066
- De Wijkerslooth J. Twee lacunes in de euthanasieregeling. Opportuun 2003; 9: 2
- Dunlop RJ, Ellershaw JE, Baines MJ ea. On withholding nutrition and hydration in the terminally ill: has palliative medicine gone too far? A reply. Journal of medical ethics 1995; 21: 141-143
- Dupuis HM. Wel of niet behandelen? Baat het niet, dan schaadt het wél. Baarn: Ambo, 1994
- Emanuel EJ, Emanuel LL. The promise of a good death. The Lancet 1998; 351: s1121-s1129
- Emanuel LL. Facing requests for physician-assisted suicide. Journal of the American Medical Association 1998; 280: 643-647
- Fainsinger R, Miller MJ, Bruera E ea. Symptom control during the last week of life on a palliative care unit. Journal of palliative care 1991; 7: 5-11
- Fainsinger RL, Waller A, Bercovici M ea. A multi-centre international report of sedation for uncontrolled symptoms in terminally ill patients. Palliative medicine 2000; 15: 257-265
- Gevers JKM. Zelfbeschikking rond het levenseinde. Tijdschrift voor gezondheidsrecht 2003; 27: 314-320. (2003a)

- Gevers S. Terminal sedation: a legal approach. *European journal of health law* 2003; 10: 359-367. (2003b)
- Griffiths J, Bood A, Weijers H. *Euthanasia and law in the Netherlands*. Amsterdam: Amsterdam University Press, 1998
- Groenewoud JH. *End-of-life decisions in medicine. Empirical studies on practices and attitudes in the Netherlands (academisch proefschrift)*. Rotterdam: Erasmus Universiteit Rotterdam, 2002
- Harris J. The philosophical case against the philosophical case against euthanasia. In: Keown J (ed.). *Euthanasia examined. Ethical, clinical and legal perspectives*. Cambridge: Cambridge University Press, 1995: 36-45
- Jacobs FCLM. Medisch zinloos handelen en zinloos medisch handelen. In: Berghmans RLP, De Wert GMWR, Van der Meer C (red.). *De dood in beheer. Morele dilemma's rondom het sterven*. Baarn: Ambo, 1991: 59-81
- Janssens RJPA, Ten Have HAMJ, Zyllicz Z. Hospice and euthanasia in the Netherlands: an ethical point of view. *Journal of medical ethics* 1999; 25: 408-412
- Janssens R, Willems D. *Ethische vragen in de palliatieve zorg*. Houten: Bohn Stafleu Van Loghum, 2001
- Janssens R, Wijn AM, Zyllicz Z ea. Controversen rondom terminale sedatie. *Tijdschrift voor gezondheidsethiek* 2002; 12: 79-83
- Janssens R, Willems D, Reuzel R ea. Morele overwegingen bij terminale sedatie. In: Verkerk MA, Hartoungh R (red.). *Ethiek en palliatieve zorg*. Assen: Van Gorcum, 2003: 154-165
- Keown J (ed.). *Euthanasia examined. Ethical, clinical and legal perspectives*. Cambridge: Cambridge University Press, 1999
- Lawton J. *The dying process: patients' experiences of palliative care*. London: Routledge, 2000
- Leenen HJJ. *Handboek gezondheidsrecht, deel 2: Gezondheidszorg en recht*. Houten: Bohn Stafleu Van Loghum, 1996 (3^e druk)
- Leenen HJJ. *Handboek gezondheidsrecht, deel 1: Rechten van mensen in de gezondheidszorg*. Houten: Bohn Stafleu Van Loghum, 2000 (4^e druk, bewerkt door Leenen HJJ, Gevers JKM)
- Leenen HJJ. *Levensbeëindiging zonder verzoek*. *Medisch contact* 2001; 56: 775-777
- Legemaate J. De wettelijke regeling van levensbeëindiging op verzoek en de inhoud van de zorgvuldigheidseisen. In: Legemaate J, Dillmann RJM (red.). *Levensbeëindigend handelen door een arts op verzoek van de patiënt*. Houten: Bohn Stafleu Van Loghum, 2003: 28-47
- Lichter I, Hunt E. The last 48 hours of life. *Journal of palliative care* 1990; 6: 7-15
- Melief WBAM. *De zorg voor terminale patiënten en de omgang met euthanasievragen door hulpverleners in de thuiszorg en de intramurale zorg*. Den Haag: Nederlands Instituut voor Maatschappelijk Werk Onderzoek, 1991
- Nuland SB. *How we die*. New York: Alfred A. Knopf, 1993
- Nuy M, Hoogerwerf A. De verlegenheid ten aanzien van het menselijk beheer. Over de grens tussen normaal en buitengewoon medisch handelen. *Tijdschrift voor gezondheidsethiek* 2000; 10: 121-125
- Orentlicher D. The Supreme Court and physician-assisted suicide. *New England journal of medicine* 1997; 337: 1236-1239
- Orentlicher D. The Supreme Court and terminal sedation. In: Battin MP, Rhodes R, Silvers A (eds). *Physician assisted suicide. Expanding the debate*. New York: Routledge, 1998: 301-311
- Payne SA, Langley-Evans A, Hillier R. Perceptions of a 'good' death: a comparative study of the views of hospice staff and patients. *Palliative medicine* 1996; 10: 307-312
- Pool R. *Vragen om te sterven. Euthanasie in een Nederlands ziekenhuis*. Rotterdam: WYT Uitgeefgroep, 1996
- Pool R. Euthanasie: de stijl van de dokter. In: Legemaate J, Dillmann RJM (red.). *Levensbeëindigend handelen door een arts: tussen norm en praktijk*. Houten: Bohn Stafleu Van Loghum, 1998: 204-215
- Quill TE. The ambiguity of clinical intentions. *The New England journal of medicine* 1993; 329: 1039-1040
- Quill TE. A midwife through the dying process. *Stories of healing and hard choices at the end of life*. Baltimore: Johns Hopkins University Press, 1996
- Quill TE, Dresser R, Brock DW. The rule of double effect: a critique of its role in end-of-life decision-making. *New England journal of medicine* 1997; 337: 1768-1771. (1997a)
- Quill TE, Lo B, Brock DW. Palliative options of last resort. *Journal of the American Medical Association* 1997; 278: 2099-2104. (1997b)
- Rachels 1986: Rachels J. *The end of life*. Oxford: Oxford University Press, 1986
- Reuzel RPB, Janssens MJPA, Crul BJP. Terminale sedatie in de laatste levensfase. *Nederlands tijdschrift voor pijn en pijnbestrijding* 2002; 22: 36
- Searle JR. The intentionality of intention and action. *Cognitive science* 1980; 4: 47-70

- Smith R. A good death. *British medical journal* 2000; 320: 129-130
- Stone P, Phillips C, Spruyt O ea. A comparison of the use of sedatives in a hospital support team and in a hospice. *Palliative medicine* 1997; 11: 140-144
- Swart SJ, Van Zuylen L, Van der Rijt CCD ea. Sterven kost tijd. *Medisch Contact* 2003; 58: 910-911
- Swarte N. Euthanasia among hospitalised cancer patients and the consequences for the bereaved. (academisch proefschrift) Utrecht: Universiteit Utrecht, 2003. (2003a)
- Swarte NB, Van der Lee ML, Van der Bom JG ea. Effects of euthanasia on the bereaved family and friends: a cross sectional study. *British medical journal* 2003; 327: 189-192. (2003b)
- Thoms A, Sykes N. Opioid use in last week of life and implications for end-of-life decision-making. *The Lancet* 2000; 356: 398-399
- Van Dam H. Versterven is geen zaak voor justitie. *Volkskrant* 5 juli 2003
- Van Deijck RHPD, Rondas AALM, Berghmans RLP. Terminale sedatie bij wilsbekwame patiënten: geen overwegende morele bezwaren in de medische literatuur. *Nederlands tijdschrift voor geneeskunde* 2003; 147: 2479-2483
- Van Delden H. *Medicine based ethics*. Utrecht: Universiteit Utrecht, 2003
- Van der Wal G, Van der Maas PJ. Euthanasie en andere medische beslissingen rond het levenseinde. De praktijk en de meldingsprocedure. Den Haag: SDU Uitgevers, 1996
- Van der Wal G, Van der Heide A, Onwuteaka-Philipsen BD ea. *Medische besluitvorming aan het einde van het leven. De praktijk en de toetsingsprocedure euthanasie*. Utrecht: De Tijdstroom, 2003
- Van Tol D. Tussen pijnbestrijding en euthanasie. De rol van intenties in het sterfgevallenonderzoek. *Ethiek en maatschappij* 4 (2001) 1: 46-54
- Ventafriidda V, Ripamonti C, De Conno F ea. Symptom prevalence and control during cancer patients' last days of life. *Journal of palliative care* 1990 6: 7-11
- Verhagen EH, Eliel MR, De Graeff A ea. Sedatie in de laatste levensfase. *Nederlands tijdschrift voor geneeskunde* 1999 143: 2601-2603
- Verweij MF, Kortmann FAM. Abstineren: argumentatie voor staken of afzien van levensverlengend handelen. *Nederlands tijdschrift voor geneeskunde* 1999 143: 145-148
- Verhagen EH, Hesselmann GM, Besse TC ea. Palliatieve sedatie. *Nederlands tijdschrift voor geneeskunde* 2004 (aanvaard voor publicatie)
- Verslag van de begeleidingscommissie van het onderzoek naar medische beslissingen rond het levenseinde door professor Van der Wal en professor Van der Maas, 2003.
- World Health Organization. *Definition of palliative care*. Geneva: WHO, 2002
- Wilkes E. On withholding nutrition and hydration in the terminally ill: has palliative medicine gone too far? A commentary. *Journal of medical ethics* 1994; 20: 144-14
- Willems D. Een passend einde. Pre-advies Nederlandse Vereniging voor Bio-ethiek. Groningen: NVBE, 2003

Appendix 1

Standing Committee on Medical Ethics and Health Law

(Beraadsgroep Gezondheidsethiek en Gezondheidsrecht)

prof. JA Knottnerus, president of the Health Council of the Netherlands; Health Council, The Hague, president

prof. JKM Gevers, professor of health law; Academic Medical Centre, University of Amsterdam, vice-president

prof. ID de Beaufort, professor of medical ethics; Erasmus University Medical Centre, Rotterdam
dr GCML Christiaens, gynaecologist; University Medical Centre, Utrecht

prof. RPTM Grol, professor of quality of care; University Medical Centre St Radboud, Nijmegen

prof. GRJ de Groot, professor of health insurance law; Free University, Amsterdam

prof. JCJM de Haes, professor of medical psychology; Academic Medical Centre, University of Amsterdam

RM den Hartog-van Ter Tholen; Ministry of Health, Welfare and Sports, The Hague, advisor

prof. GA den Hartogh, professor of ethics; University of Amsterdam

dr AC Hendriks, health lawyer; Dutch Equal Treatment Commission, Utrecht

dr WLM Kramer, pediatric surgeon and traumatologist; Wilhelmina Childrens' Hospital, University Medical Centre, Utrecht

prof. FE van Leeuwen, professor of epidemiology; Netherlands Cancer Institute, Amsterdam

dr M van Leeuwen, executive director of the Health Council of the Netherlands, adviser

dr J Legemaate, health lawyer; Royal Dutch Medical Association (KNMG), Utrecht

prof. HDC Roscam Abbing, professor of health law; Utrecht University

prof. M de Visser, vice-president of the Health Council of the Netherlands; Health Council, The Hague

prof. GMWR de Wert, professor of biomedical ethics; Institute of Health Ethics, Maastricht University

prof. MA Verkerk, professor of medical ethics; University Medical Centre, Groningen

prof. DL Willems, professor of medical ethics; Academic Medical Centre, University of Amsterdam

A Bood; Health Council of the Netherlands, The Hague, scientific secretary

dr WJ Dondorp; Health Council of the Netherlands, The Hague, scientific secretary

