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Special Article

A National Guideline for Palliative Sedation in The Netherlands

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Abstract

The first national guideline on palliative sedation in The Netherlands has been adopted by the General Board of the Royal Dutch Medical Association. By law, the physician is obliged to take this guideline into consideration. In this paper, we present the main principles of the guideline. Palliative sedation is defined as the intentional lowering of consciousness of a patient in the last phase of his or her life. The aim of palliative sedation is to relieve suffering, and lowering consciousness is a means to achieve this. The indication for palliative sedation is the presence of one or more refractory symptoms that lead to unbearable suffering for the patient. Palliative sedation is given to improve patient comfort. It is the degree of symptom control, not the level to which consciousness is lowered, which determines the dose and the combinations of the sedatives used and duration of treatment. Palliative sedation is normal medical practice and must be clearly distinguished from the termination of life. J Pain Symptom Manage 2007;34:666–670. © 2007 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Palliative sedation, guideline

Introduction

Over the past few years, a great deal of discussion has taken place in The Netherlands about “terminal sedation,” also known as palliative sedation. The discussion was about the criteria and the conditions that must be met,

and also about the relationship between palliative sedation and euthanasia. In 2003, the former Chief Prosecutor, Joan De Wijkerslooth, suggested that terminal sedation should perhaps be covered by the Euthanasia Act. Minister Piet Hein Donner and Secretary of State Clémence Ross-van Dorp responded by informing the Lower House that terminal sedation was normal medical practice.¹

In the third study of medical decisions in end-of-life care, published in 2003, data on terminal sedation appeared for the first time.² In its reaction to this study, the government stressed that it was important for the medical profession itself to develop a national

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guideline with respect to terminal sedation. In September 2004, at the request of the Ministry of Health, Welfare and Sports, the Royal Dutch Medical Association (RDMA) appointed a committee that was given the task of drawing up this guideline. The committee consisted of a medical ethicist (chairperson), two medical oncologists, two general practitioners, two nursing home physicians, one anesthesiologist, two nurses, a health lawyer, and a health scientist. All authors of this paper were members of the RDMA committee that designed the guideline.

The committee met 11 times between October 2004 and September 2005. A literature review was performed. After a consensus was reached within the committee and a draft guideline was written, comments were given by several medical, nursing, and pharmacist associations, medical ethicists, and the Ministry of Justice. In November 2005, the final version of the guideline was adopted by the General Board of the RDMA.³ By implication, the guideline is now part of the physician's professional standard(s). By law, the physician is obliged to act according to these standard(s). On December 7, 2005, the guideline was offered to the Secretary of State for Health, Welfare and Sports.

There are a limited number of guidelines or recommendations for clinical practice.^{4–14} One of these was recently published as a national guideline,¹⁰ some were developed at an institutional level by a specific task force,^{5,9,13} and others reflect the opinion and experience of the authors.^{4,6–8,11,12,14} Recently, recommendations for standards for palliative sedation were published by a task force of the European Association for Palliative Care.¹⁵ In this paper, we present the main principles of the guideline.

What Is Palliative Sedation?

The terms palliative sedation, sedation in the final phase of life, terminal sedation, or deep sedation may have different meanings, but are often used as synonyms. In the guideline, the term “palliative sedation” is preferred, as it makes quite clear that this sedation takes place in the framework of palliative care. Several definitions have been

proposed in the literature.^{15–19} The definition of palliative sedation used in the guideline is as factual as possible; palliative sedation is “the intentional lowering of consciousness of a patient in the last phase of his or her life.” The objective of palliative sedation is to relieve suffering (caused by refractory, i.e., untreatable, symptoms), and lowering consciousness is a means to achieve this. It is very important that palliative sedation is given for the right indication, proportionally and adequately. Proportionally means that consciousness is lowered only to the level necessary and sufficient to achieve the desired level of symptom alleviation.^{14,15,17,20} The level of reduction of consciousness to achieve this end may vary from superficial to deep. The assessment and decision-making processes must focus on adequate relief of the patient's suffering, so that a peaceful and acceptable situation is created. Palliative sedation is given in the last phase of life, in the imminently dying patient.

According to the guideline, palliative sedation may be used in two ways: 1) continuous sedation until death or 2) short-term or intermittent sedation. The ethical, legal, social, and political debate that has taken place regarding “terminal sedation” was mainly about continuous sedation until death.

Indication and Conditions

As in all other guidelines,^{4–15} the indication for palliative sedation is formulated as follows: the presence of one or more refractory symptoms, which leads to unbearable suffering for the patient. A symptom is or becomes refractory if none of the conventional treatments are effective (within a reasonable time frame) and/or these treatments are accompanied by unacceptable side effects.^{6,15} Pain, dyspnea, and delirium are the most common refractory symptoms that in clinical practice lead to the use of palliative sedation.^{5,6,15,17}

Another condition (which only applies to deep and continuous sedation until death) is that death must be expected within one to two weeks.^{4,18} This condition is also mentioned in other guidelines.^{5,8,10,13–15} In the guideline, the assumption is made that if deep and continuous sedation is administered (and the patient is, therefore, unable to take

fluids him- or herself), artificial hydration will not contribute to the relief of suffering^{4,15,21,22} and may, in fact, have disadvantages, such as the need for a subcutaneous or intravenous cannula and the possible increase of some symptoms and signs (e.g., pain, edema, bronchial secretion, and urinary incontinence). Although the decision to discontinue or not to start artificial hydration should be seen as a separate decision,¹⁵ the guideline recommends in general not to give fluids to a deeply sedated patient. It should be noted in this regard that almost all patients for whom deep palliative sedation is considered have already stopped taking fluids prior to sedation. If life expectancy is less than two weeks, it is assumed that withdrawing artificial hydration will not hasten death. If life expectation is longer, the situation is different, because in that case, the patient would die sooner due to dehydration than would otherwise be the case.

Decision Making

In a situation of severe suffering caused by refractory symptoms, palliative sedation may come up for discussion as the result of a request—explicitly or implicitly—from the patient and/or his or her family. Health care professionals also may take the initiative. In the guideline, it is stated that consideration of palliative sedation demands an exploration of the patient's situation. Relevant information should be obtained from the patient, the family, and the health care providers involved; this should lead to an adequate assessment of the patient's condition. Continuity of teamwork, good coordination, exchange of information, and communication between the various care providers are essential. Lack of any of these may lead to inadequate assessment, information discrepancies, and to unrest. Optimal agreement between all those involved, especially in the home situation, is crucial.

Eventually, this should lead to a decision by the physician responsible for the treatment. Palliative sedation is regarded as a normal medical procedure, although one used rarely and only under exceptional circumstances. Elements of the decision are the aim and level (superficial or deep) of the sedation, choice of the correct medication, and dosage. Notes on the decision-making process and the

considerations playing a role in it are to be recorded in the patient's file, including any consultation that has taken place with the patient and/or his or her family, between the care providers, and with any specialists involved. In case of disagreement between the medical team and the relatives about what is in the patient's best interest, the doctor has the final say in the decision making (as is regulated in section 465 of the Dutch Patients' Rights Act).

In acute life-threatening (e.g., acute suffocation due to tumor growth or bleeding) situations, the treating physician may decide to initiate palliative sedation without consultation. In these cases, the steps referred to above must then be carried out after starting sedation.

Consultation

Just as in all other forms of medical treatment, there must always be sufficient expertise on which to base the decision to initiate palliative sedation. A doctor who is responsible but has insufficient knowledge of the treatment of severe symptoms, is uncertain about the correctness of the indication, and/or has insufficient knowledge on how to administer sedatives should consult an expert, preferably a palliative care specialist.^{4,5,7,9–11,13–15}

Administering Sedation

The initiation of palliative sedation is an emotionally charged occasion, especially if it leads to a rapid loss of consciousness so that communication with the patient is lost. The doctor should be present when it is initiated, because sometimes intervention is necessary. In the subsequent phase, the administration of sedation can be left largely to nurses and carers, if necessary.

In the guideline, the administration or dose increasing of opioids or other nonprimarily sedative medications with the implicit or explicit objective of producing sedation is regarded as improper use of these medications, as sedation may occur at doses that may be associated with undesirable effects, and even high doses may fail to induce sedation.^{4,15,18,22}

When palliative sedation is started, usually a stepwise approach is taken. Midazolam is the drug of first choice. If the response to an optimal dose of midazolam is inadequate, the

team should check that the route of administration and the medication are in order and whether any reversible interfering factors (such as a full bladder or constipation) are playing a role. Only after excluding these factors should drugs such as levomepromazine, phenobarbital, or propofol be considered.

Other Aspects

Good documentation is essential. The relevant data about the patient and his or her situation must be recorded in the file: why the decision was made to initiate palliative sedation, how it was administered, an assessment of its effect, and what criteria must be met to adjust the dosage. The treating physician should visit the patient at least once a day.

Optimal palliative care also includes giving attention, support, and counseling to the patient's family and close friends. Both during the course of events leading up to palliative sedation and during its administration, they play an important role. They function as carers, observers, informants, and representatives of the patient, in addition to their role as partner, family member, close friend, or acquaintance. They go through their own process of uncertainty, feelings of guilt, fear, sorrow, and mourning. Giving information and explanations to the family, working with them, and assessing the situation with them are essential for a satisfactory procedure and good parting.

There should also be attention for the team members involved: care for the carers. Throughout the whole process, care and support should be available for the various care providers who are involved in the patient's situation. This requires good communication, reflection, and support for care providers.

Palliative Sedation and Euthanasia

In the period preceding the appearance of the guideline, discussion took place about the position of continuous sedation until death in comparison to life-terminating treatment, in particular, euthanasia. The guideline expresses the view that palliative sedation is normal medical practice and must be clearly distinguished from the termination of life.

Palliative sedation is a way to reduce conscious experience of symptoms and, therefore,

of severe suffering. Palliative sedation differs from euthanasia in that palliative sedation is not aimed at the termination of life. There is no evidence that appropriately administered palliative sedation shortens life.²³ This means that palliative sedation and euthanasia must be clearly distinguished from each other. Palliative sedation is for patients who do not want to suffer any more but do not want to end their lives either. This means that palliative sedation that is administered for the correct indication, in the correct dose, and in an adequate way is not a "shortcut" to achieving the same goal as euthanasia, namely to end life, but more slowly and without observing the requirements and procedures set for euthanasia. Palliative sedation is not "slow euthanasia."^{24–26}

Conclusion

Initially, palliative sedation had been associated with the termination of life. It should not be. There is no evidence that proportionally administered palliative sedation shortens life. In recent years, it has been stressed more and more often that palliative sedation is normal medical practice. This view is the point of departure in the new guideline issued by the RDMA. Nevertheless, it is still important to define explicit criteria and conditions for the use of palliative sedation in order to contribute to sound medical practice in this area. It is in this light that the contents of the guideline should be seen. In this guideline, the committee has gathered current knowledge and experience based on several previously existing regional guidelines, the national and international literature and the opinions of experts within and outside the committee. Advancing insights will undoubtedly lead to adjustments in the guideline. For the time being, it is important that the debate about palliative sedation is stripped of spurious elements and that physicians and other care providers are aware of the standards and points of departure for sound practice.

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