Palliative sedation at the end of life – revised guidelines

Palliative sedation of patients at the end of life involves a number of medical, ethical and legal challenges. As a support to doctors who provide this treatment to patients who cannot be helped in any other way, the Norwegian Medical Association prepared a set of guidelines in 2001. These have now been revised and adopted by the national board in June 2014. This work and some key points in the new guidelines will be presented here.

The form of treatment referred to as «palliative sedation» came to widespread attention in 1998, through the so-called «Bærum affair». A doctor at Bærum Hospital accused a colleague of having committed illegal euthanasia – previously known by the misnomer «active euthanasia» (1) – after a cancer patient who was suffering great agony had been sedated until he died. The matter was reported to the police. In December 2001, the Director of Public Prosecutions dropped the case because of «insufficient evidence». The incident gave rise to intense and comprehensive debate (2). The case also entailed major consequences for a number of people. After massive pressure exerted through the media, Anne Alvik, Director of Health, decided to resign, and many doctors became reluctant to provide sufficient palliative treatment for fear of being accused of performing euthanasia.

In the wake of the incident, the Norwegian Medical Association prepared detailed guidelines for what became known as «palliative sedation for the dying» (3). Their goal was to ensure that the small group of patients who are subject to intolerable suffering in spite of symptomatically palliative treatment can have access to this form of treatment within a framework which is clinically, ethically and legally justifiable. One key concern was that life should not be shortened by this treatment (4), but that the patient should die from his or her basic affliction. Patients should be closely monitored with regard to effectiveness and adverse effects, which presupposes hospitalisation. This type of treatment is now widely recognised internationally as a necessary measure in extreme situations, including by the World Medical Association (5).

After the guidelines

The working group that prepared the guidelines from 2001 assumed that they would need revision (3). Feedback from doctors also indicated that a revision was called for (6). For example, it has been reported that some patients with intractable symptoms fall outside the scope of the guidelines, since they are expected to live for more than two weeks.

A new working group, consisting of the authors of this article, was appointed by the national board of the Norwegian Medical Association in 2013 to revise the guidelines (7), and the revision was adopted in June 2014 (8).

Work started by collecting information from a number of clinicians regarding prevailing practice in terms of this form of treatment. Cancer patients in particular have received palliative sedation (9), and we wished to find out whether the guidelines were perceived as too restrictive. We also raised the question of whether mental symptoms at the end of life ought to be accepted as a sole indication. Moreover, we asked for input regarding which items were in need of revision, and whether palliative sedation could also be provided by municipal health services.

«The patient's needs should be the guiding principle»

Confusion around the definition?

The definition of this form of treatment is critically important: «By palliative sedation is meant pharmacological depression of the level of consciousness in order to alleviate suffering that cannot be relieved in any other way» (8). This involves the use of drugs to reduce the level of consciousness of a patient for whom death is approaching. The treatment often needs to continue until death occurs (9).

Acute sedation in case of unexpectedly occurring agony and sedation during ventilator and necessary surgical treatment do not fall within this definition. Nor do the drowsiness or the reduced level of consciousness that occur in symptomatic treatment with the aid of tranquilisers and analgesics. This is established medical practice and thus ethically unproblematic. Only deep and long-lasting sedation requires ethical guidelines, since it is especially demanding and invasive (10).

Ethically crucial questions

A key question is whether waking the patient should always be attempted (6). We are open to the possibility that it may be appropriate not to do this when it is obvious that the affliction will last until the end of life. Another issue is whether deep anxiety and distress should be regarded as indications in themselves. We believe that serious and treatment-refractory mental symptoms and delirium with extreme distress and confusion, for which attempts have been made to rectify any pathophysiological causes, could be an indication.

If patients who are expected to have more than a few hours or days left to live are placed in deep and continuous «sleep», there is an increasing risk that complications could foreshorten their lives. From a treatment perspective, such possible adverse effects pose problems. A third conundrum is therefore whether it can be justifiable to provide palliative sedation to patients with treatment-refractory afflictions, even when they are not immediately «dying». The working group gives an affirmative answer to this question, since the total suffering in such cases is greater.

The clinical and ethical imperative to relieve suffering weighs heavily. This is the background to our decision to change the title of the guidelines from «to the dying» to «at the end of life». If patients with longer remaining lifespans are provided with palliative sedation, monitoring is especially crucial. The doctor in charge of treatment must take all possible precautions to ensure that the patient does not die from complications resulting from the sedation. Competence, monitoring and communication with the patient (if possible) and next of kin are especially essential when palliative sedation is administered (6).

The guidelines also refer to fluid infusion. Here, we conclude that this will not normally be necessary if the patient has stopped drinking before sedation treatment is initiated. On the other hand, if the patient is ingesting fluids in any significant amount or is receiving parenteral fluids before palliative sedation is initiated, parenteral fluid infusion should continue. The amount of fluid should be adapted to the patient's basic needs and continually assessed. This also applies to all forms of pharmacological treatment.

This is a form of treatment that should only be used in extreme cases and under

specific conditions that are justifiable in medical, ethical and legal terms (8). The treatment can be abused by accelerating the death process through a deliberately disproportional increase in drug dosages. This is tantamount to «slow» euthanasia if the patient has requested such overdoses. If no such request has been made, this will be either an involuntary or non-voluntary medical homicide, depending on whether the patient is competent to provide consent or not (1, 10). Of course, it is essential to prevent these three deliberate, illegal forms of expediting death.

The patient's needs should be the guiding principle, and professional competence, experience and sound medical judgement are thus of the highest importance. This has an impact on whether the treatment may also be provided in nursing homes or in the patient's own home. Another item states that if it is deemed necessary to depart from the guidelines, this decision must be discussed at the managerial level and documented.

The hearing round showed widespread support for the guidelines, even though they evoked some critical remarks. Some feared that the change made to the title could risk a slippery slope leading to acceptance of euthanasia. We believe that this objection is groundless, for the following reasons: In contrast to palliative sedation, euthanasia is not a form of treatment (1, 10). Even though the sedation may involve a risk of premature death, this will never be the intention, provided that the guidelines are complied with. In the case of euthanasia, on the other hand, premature death – or more correctly: the quickest possible death – is the very intention (1, 10).

Now what?

Far too many sets of guidelines remain «well-kept secrets» (11). The revised guidelines (8) are a support to professionals who need to handle especially difficult cases, so that they can provide the optimal – ethically and legally justifiable – treatment to patients at the end of life. This presupposes that the relevant professional communities do their part to communicate them to the clinical level.

Reidun Førde
Lars Johan Materstvedt
lars.johan.materstvedt@ntnu.no
Trond Markestad
Ulf E. Kongsgaard
Sebastian von Hofacker
Siri Brelin
Stephan Ore
Morten Laudal

Reidun Førde (born 1950), MD, PhD, and professor at the Centre for Medical Ethics, University of Oslo. She was chair of the Council for Medical Ethics in the period 1998–2005, head of the working group that authored the *National manual for decision-making pertaining to restriction of life-prolonging treatment for seriously ill and dying patients* (2009) and chaired the revision of the same, which resulted in *Decision-making processes in the restriction of life-prolonging treatment* (2013).
The author has completed the ICMJE form and declares no conflicts of interest.

Lars Johan Materstvedt (born 1960), PhD, and professor of philosophy at the Department of Philosophy and Religious Studies, Norwegian University of Science and Technology (NTNU). He is an expert in medical ethics at the professor level. He is a former researcher in the Norwegian Cancer Society and head of The Ethics Task Force on Palliative Care and Euthanasia, European Association for Palliative Care (EAPC).
The author has completed the ICMJE form and declares no conflicts of interest.

Trond Markestad (born 1945), MD, PhD, professor of paediatrics, research coordinator at the Division of Paediatrics, Haukeland University Hospital, and research advisor at Innlandet Hospital Trust. He was chair of the Council for Medical Ethics in the period 2006–2013.
The author has completed the ICMJE form and declares no conflicts of interest.

Ulf E. Kongsgaard (born 1949), MD, PhD, senior consultant and professor of anaesthesiology at the Emergency Department, University of Oslo. He has worked with all aspects of anaesthetics, in recent years especially with cancer-related pain palliation.
The author has completed the ICMJE form and declares no conflicts of interest.

Sebastian von Hofacker (born 1964), MD, anaesthesiologist and senior consultant. He works at the Competence Centre for Palliative Treatment, Western Norway Health Authority, and at Haraldsplass Deaconal Hospital, where he is chair of the Committee on Clinical Ethics. He has 15 years of experience in palliative medicine.
The author has completed the ICMJE form and declares no conflicts of interest.

Siri Brelin (born 1963), MD, specialist in general practice, senior consultant and PhD scholar at the Competence Centre for Palliative Care, Oslo University Hospital. She has been a member of the Council for Medical Ethics since 2014.
The author has completed the ICMJE form and declares no conflicts of interest.

Stephan Ore (born 1954), MD, former GP, specialist in general practice and chair of the Norwegian Association for Nursing-Home Medicine. He works at Oppsalhjemmet nursing home, Norlandia Care.
The author has completed the ICMJE form and declares no conflicts of interest.

Morten Laudal (born 1953), MD, GP at Brevik Medical Centre, with experience from medical practice in nursing homes, general practice and public health.
The author has completed the ICMJE form and declares no conflicts of interest.

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