



UNOFFICIAL TRANSLATION

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(To
The Government
Ministry of Health and Social Affairs
Ministry of Justice)

The National Council on Medical Ethics (SMER) hereby presents a memorandum prepared by a Council working group on considerations in the final stage of life. The memorandum is commented on by the Council in this letter.

Introduction

End-of-life issues have recently attracted a great deal of attention. Both in Sweden and internationally, the fact that people choose to go to Switzerland to terminate their lives, that active euthanasia is permitted in the Netherlands and that physician-assisted suicide is permitted in the state of Oregon is widely debated. In Sweden, discussions within the medical profession about decisions in the final stage of life, have recently lead to new guidelines from the ethics delegation of The Swedish Society of Medicine (SLS) about palliative sedation of dying patients (2003) and withholding and withdrawing life-sustaining treatment (2007). The Section for Anaesthesia and Intensive Care at SLS has produced national guidelines for withholding and withdrawing life-sustaining treatment within Swedish intensive care (2006).

SMER is an advisory body to the Government that shall review medical-ethics issues in a societal perspective. Since the end of the 1980's, the Council has frequently dealt with questions such as care and other measures at the end of life. These discussions were resumed in 2006 and the Council has, for example, participated in a research seminar in the Netherlands on the consequences of the law Termination of Life on Request and Assisted Suicide (Review Procedures) Act that came into force in April 2002. The Council has discussed various issues concerning life-support treatment, consulted invited experts on palliative care and a conference on end-of-life issues (the so-called Ethics Day) was organised by the Council in January 2008, where the participants were mainly health care staff.

Alleviating or palliative care

SMER has studied the report of the National Board of Health and Welfare from December 2006 which shows that alleviating or palliative care in Sweden has developed and improved in the last few years. However, it also appears that there is a need for continuing professional development for staff in palliative care, that the supply of staff with competency in palliative care is insufficient, that equally good palliative care cannot be offered all over the country and that improved follow-up is desirable.

It is of the utmost importance that such measures are taken. SMER is concerned about the report from the National Board of Health and Welfare and considers that decision-makers within the educational system, municipalities and county councils must take further action to improve the supply and quality of palliative care in the whole country.

Whether or not the patient can make decisions about his/her own death is not independent of the conditions within palliative care. But this discussion mainly concerns what decisions about care in the final stage of life can be made in individual and special cases rather than how palliative care at large is organised and carried out. The issue is complex because palliative care is not a homogeneous activity under a single authority but is provided in several contexts and by different care providers.

Decisions in the final stage of life

SMER has been influenced among others by the report *Self-determination and Care at the End of Life* published by the German Ethics Council (Nationaler Ethikrat) in 2006. This report formulates a number of recommendations about what should be allowed in different situations and according to different criteria. The report is not unanimous in all parts; the German Council reports disagreements on certain recommendations.

In the spring of 2007, SMER appointed an internal working group that has prepared a memorandum as a basis for the Council's discussions. Modelled on the report from the German Council, the memorandum from the working group distinguishes a number of situations at the end of life that require difficult and potentially controversial decisions. This concerns decisions to:

- 1) withhold life-sustaining treatment,
- 2) withdraw life-sustaining treatment,
- 3) offer palliative treatment and palliative sedation,
- 4) offer assistance of a physician in prescribing lethal doses of drugs in the case of self-determined termination of life, and
- 5) offer active assistance of a physician in the case of self-determined termination of life

The working group and the Council find that decisions according to the first three items can be made within the framework of existing regulations. However, there is considered to be some uncertainty about the more detailed prerequisites for palliative sedation.

Decisions in accordance with the last two items are not compatible with Swedish Law. It is important that ethical and legal aspects of these situations are further reviewed.

Palliative sedation

When a physician, together with the other health care staff concerned and in accordance with good clinical practice, finds that curative (healing) treatment is no longer meaningful, this treatment is to end and be replaced by palliative care. Depending on the needs of the patient, this can for example consist of treatment of pain, anxiety, dizziness, nausea, dyspnea and cramps.

If or when these efforts do not have the desired effects, so-called palliative sedation is an option, which means a medically induced decrease in consciousness to a level where the patient is not bothered by his/her symptoms. This measure is taken after consultation with the patient if he/she is capable of making decisions. Also relatives (next of kin) should normally be informed about the development. If the patient is not capable of making decisions, the relatives are consulted in order to find out what the patient would have wished.

The supply of nutrition and hydration is seldom meaningful in a medical sense at this stage and can even aggravate the symptoms of the patient. Thus, this treatment is also terminated when starting palliative sedation, after due consideration of the individual care situation, culture and religion. Continued good nursing care goes without saying.

The patient is continuously monitored and, in principle, the depth of sedation shall regularly be decreased to evaluate the status of the patient. If, however, it is estimated that the patient will only survive for a few days or a week with an unchanged condition, sedation can be maintained until the patient passes away.

This procedure, which consists of far more detailed steps and controls than what can be described here, should be considered as established and also finds support in the general guidance of the National Board of Health and Welfare and the guidelines of The Swedish Society of Medicine. The working group does, however, point out that there is variation in practice and that there is still some uncertainty within the health-care sector as to what really applies. A factor of increasing importance is the growing consideration of the patient's wishes about his/her own care.

In its memorandum, the working group points out the situation when a patient who is capable of making decisions fulfils all criteria for palliative care and himself/herself asks for continuous palliative sedation, including the termination of the possible supply of nutrition and hydration, despite the fact that, according to the physician's evaluation, death is not imminent and the patient would probably survive longer than a week or so without such treatment. This would be comparable to the patient's right to refuse continued life-sustaining treatment and to the possibility thereafter of being sedated as appears from the guidelines of The Swedish Society of Medicine from 2007 for terminating life-sustaining treatment.

SMER is of the opinion that patients should have an increased influence on their palliative care and about if and when palliative sedation is to be used.

Self-determined termination of life in special cases

The working group also directs attention to a group of incurable diseases, which are often discovered long before death occurs and develop with increasingly severe physical and sometimes mental symptoms until the patient passes away. The working group proposes that in these very special cases, the physician in charge should, at the patient's request, be permitted to prescribe medicine in such a dose to allow the patient the option to terminate his/her own life himself/herself. Such a prescription should be preceded by a careful examination and control by a second physician.

When this item was discussed by the Council, the majority tended to agree with the proposal concerning these very special cases. At the same time, it was questioned by some in the Council whether the expression of the patient's wishes in such situations could always be considered to be authentic and autonomous. Patients can be subjected to pressure from relatives and, even if this is not the case, convince themselves that they are a burden to their family. Furthermore, it is a delicate task to pedagogically explain the scope for such a procedure in light of the efforts of society to prevent suicide.

According to international law, a patient's wish to die never entails any right to terminate life through the actions of another person. However, there seems to be some scope for individual countries to determine what risks might occur by weakening the prohibition against physician-assisted suicide, for example by making it possible for a physician who so wishes to, under very special circumstances, fulfil a patient's request. The Council finds that this would require changes in the Swedish regulatory framework. A majority of the Council is of the opinion that this question should be further reviewed as well as the more detailed conditions and consequences of such changes.

Active assistance from a physician in self-determined termination of life

During the Council's discussions about active assistance from a physician in self-determined termination of life (item 5 of the working group), several members and experts in the Council gave their support to such a possibility in very special circumstances, such as (i) when a patient who is capable of making decisions cannot carry out such a measure himself/herself according to item 4 but otherwise fulfils all criteria or (ii) when an infant is suffering from a very painful, incurable and lethal disease. The majority of the Council did not share this view, but found it useful that all parts of the proposal from the group be subject to public debate.

Uncertainties and general questions

During the SMER discussions, some issues were identified where problems of assessment occurs. A basic question concerns what is a medically meaningful treatment and by whom this is determined. Another question is the time factor, i.e. how the implementation of certain measures shall depend on the length of the remaining period of time before, according to the physician, the patient is

likely to die. SMER is of the opinion that the patient himself/herself should have an increased influence on decisions about continuous palliative sedation.

A third question in this context is whether and how the confidence in the health care sector is affected by wider possibilities for continuous palliative sedation, physician-assisted self-determined termination of life and active assistance by a physician in self-determined termination of life. The confidence in health care is probably shaped by a large number of factors such as earlier experience, how the patients are being treated and transparency when it comes to decisions about care, and the conviction that the decisions are made in the patient's best interest and in accordance with good clinical practice. It is also important that patients and their family feel that they can take part in the decision-making. The Council considers that an increase in influence for the patient also when it comes to decisions about measures in the final stage of life is of great importance in this context.

When it comes to end-of-life care, the question of legal representatives (proxy) is of particular importance. The Council wishes to remind the Government that four years have now passed since proposals were made for clearer guidelines concerning representatives for adults with an insufficient decision-making capacity in health care and the introduction of a so-called end-of-life directive (SOU 2004:112). Such an initiative is apparently not to be expected within the next few years. This is not satisfactory. Sweden has expressed its support for the principle of advance directives (living wills) through the Recommendation of the Council of Europe R (99) 4 and several countries have adapted national legislation, the latest one being Finland. The insufficiencies in the Swedish regulations with regard to legal representatives in health care prevents a Swedish ratification of the Council of Europe bioethics convention, the so-called Oviedo Convention that was signed by Sweden in 1997. Thus, we have not been able to accede the four additional protocols that have been adopted (ETS 168 on cloning, 186 on the transplantation of organs, 195 on medical research and the additional protocol on genetic testing for medical purposes that was accepted on 7 May 2008).

Concluding words

It is important that the existing uncertainties about the legal conditions for decisions in different situations in the final stage of life are dispelled as soon as possible. Thus, it should be examined to what extent there could be an increase in patients' influence on decisions in the final stage of life. In particular, this concerns whether the patient could ask for palliative sedation. A Council majority is also of the opinion that it should be investigated whether physicians should be allowed to prescribe medicine for a self-determined termination of life in special cases.

Against this background, the Council thus hands over the memorandum of the working group and also makes it public on its web page.

For SMER

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