

UNOFFICIAL TRANSLATION

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The patient's possibility to decide about his/her own death

The aim of this document is to elucidate issues that concern decisions

- to withhold and withdraw life-sustaining treatment at the initiative of the patient and/or the medical service.
- providing palliative sedation at the initiative of the patient and/or the medical service.
- at the initiative of the patient, give him/her assistance in different kinds of self-determined terminations of life.

Questions that concern decisions in the final stage of life are closely connected to the development of knowledge within health care based on the classical medical-ethical question: what should we do in relation to what we can do? The answer to that question is, in turn, closely connected to the question of the patient's rights and position when facing and when making decisions about the final stage of life.

Background

Development in medicine and the patient's autonomy

For a little more than the last hundred years, modern medicine has developed a number of treatments that, in different ways, have made it possible for patients who previously died of diabetes, renal failure, heart failure, asthma, cancer diseases, infectious diseases, loss of blood, cardiac arrest etc. to survive and regain a more or less normal life. Medicines such as insulin, cortisone, antibiotics and cytostatic agents as well as medical interventions such as tube-feeding, hydration, blood transfusion, pacemaker, dialysis, ventilator etc. have, on the one hand, saved and prolonged the lives of many patients. But, on the other hand, it has contributed to the fact that the process of dying is sometimes prolonged for patients in the final stage of life, which can even lead to a decrease in quality of life in this final period.

This has led to discussions about when it is ethically defensible to withhold and withdraw life-sustaining treatment. These issues concern the dividing line between curative and palliative care and treatment, when going from the aim to save and preserve life to instead alleviate the suffering when, for medical reasons, it is no longer possible to cure the patient or when the patient himself/herself wishes to refrain from or end life-sustaining treatment.

In the last thirty years, there has been an increase in patients' influence and participation in decision-making that concern their own lives. This is true for investigations, preventive measures and treatments in health care. The respect for the patient's right to participate in the decision-making and the right of self-determination has grown increasingly stronger. Health care legislation points out that medical staff together with the patient shall make decisions about receiving or refraining from care and treatment. This should also concern termination of life-sustaining treatment and other wishes before and in the final stage of life.

This trend towards reinforcing the position of the patient within health care, and the emphasis on the patient's rights, participation in the decision-making and self-determination also means that it should be discussed how the patient's best interests are to be safeguarded for a patient with a decreasing or reduced decision-making capacity. This might concern very sick or very old people who, due to their condition, do not have the strength or are not able to express their wishes and values. This might, for example, also concern an unconscious patient whose wishes are expressed in a so-called advance directive.

In the last few years, several Swedish patients with neurological diseases have gone to Switzerland where they have received assistance in terminating their lives. There are also Swedish doctors who have said that they have prescribed lethal doses of medicines for patients with degenerative neurological diseases so that the patient himself/herself can, in this way, terminate his/her life in a less painful way than if the disease had been allowed to continue to develop.

There is a number of examples of patients in the final stage of life who have terminated their own lives in more or less drastic ways, by their own hand or with the aid of someone close. Most likely, there is a number of hidden cases in the suicide statistics as concerns self-determined terminations of life that are related to patients having been in a severe condition

due to illness in the final stage of life. The secretariat of *the National Council on Medical Ethics* sometimes receives questions from people with a painful disease who are in the final stage of life and who want to know whether they can get assistance in terminating their life while they are still in control. Sometimes, they express their agony about a drastic suicide being without dignity and that they might therefore want assistance from the medical service in terminating their lives or at least that a self-determined end-of-life is sanctioned (permitted) by society.

Within palliative care in Sweden, there is often the possibility of offering patients alleviating treatment in the final stage of life. Very sick patients who are subject to considerable suffering might have different wishes. Certain patients wish to live as long as possible with the best possible palliative care, even if this means a life where the disease causes severe bodily disfigurements and disability. Other patients want to be assisted in terminating their life, as soon as the bodily or mental pain becomes unbearable and the end predictably painful, in order to avoid prolonged meaningless suffering. The question is to what extent palliative medicine can fulfil all patients' wishes as concerns the choices in the final stage of life.

If a patient in the final stage of life experiences unbearable suffering, the medical service can offer the patient to be sedated until he/she passes away, so-called palliative sedation or terminal sedation. At the patient's request or often at the initiative of the medical service, all other treatments including hydration and nutrition are then terminated. As clinical routine, palliative sedation is offered in particular to patients who are so affected by their suffering that this treatment is a stage in palliative easing of symptoms.

Even if it were feasible to offer all patients concerned the best possible palliative care – even on the patient's request – it cannot be excluded that there is a group of patients in the final stage of life who do not consider that palliative medicine can fulfil their needs. The fact that already today there are patients who go to Switzerland and physicians who prescribe lethal doses of drugs in order to make a so called physician-assisted suicide possible, indicates that there is a need which is not fulfilled by health care today. Currently, we do not know how many people there are who to a larger extent would like to be able to determine for themselves how they want to die, self-determined end-of-life.

Terminology and classification

An important starting point for the discussion about an increase in patients' self-determination/participation in decisions in the final stages of life is that those patients in most cases are in the final stage of life, either because they themselves no longer want to have the care/treatment that is being offered or because they have reached a turning point where there has been a transition from curative to palliative care. Another prerequisite is that it has been excluded that these patients suffer from a psychiatric disease that can be treated. Moreover, it is assumed that the patients we are talking about experience bodily and/or mental suffering that the patient considers unbearable. It is also of relevance whether the patient is capable of making decisions and/or whether there is a care directive or whether it is possible to deduce a hypothetical will in situations where the patient is no longer capable of making decisions. In the following, we will discuss what patients can be offered in the final stage of life. We will deal with the following situations:

1) withholding life-sustaining treatment, when this is done on:

- the patient's initiative (1a-b)
- a physician's initiative (1c-d)

2) withdrawing life-sustaining treatment, when this is done on:

- the patient's initiative (2a)
- a physician's initiative (2b-c)

3) offering palliative treatment and palliative sedation, when this is done on:

- the patient's initiative (3a)
- a physician's initiative (3b)

4) offering the assistance of a physician in prescribing lethal doses of drugs in the case of a self-determined end-of-life – so-called physician-assisted suicide.

5) offering active assistance from a physician upon self-determined end-of-life.

The situations described below (1–2 + 3b) in practice already exist in Swedish health care. However, this does not mean that they are ethically uncontroversial – for example, it is a

delicate task to decide when life-sustaining treatment should be withdrawn and when continuous palliative sedation should be applied. It is important to discuss whether there is a need for regulations or clarifications regarding these situations. It is also important to discuss whether we should also allow and recommend any of the measures described in item 3a, which concerns continuous palliative sedation *at the patient's request*, and the situations in items 4 and 5.

Withholding life-sustaining treatment

1a) The medical services withhold life-sustaining treatment if a patient who is capable to make decisions so wishes. For example, it does happen that patients suffering from cancer decline cytostatic treatment despite it being considered life prolonging. Even when it is obvious that a patient might benefit from a treatment, the right of a patient who is capable of making decisions to refuse is respected. This is also the case when, for example, an older patient and/or a seriously ill patient wishes to refrain from starting a penicillin treatment when suffering from pneumonia, or refrain from initiating a supply of nutrition or hydration, with or without probe (PEG). It is mainly respect for the patient's right to self-determination that justifies going along with the patient's wishes.

1b) If the patient is not capable to make decisions and there is a so-called advance directive where the patient expresses the wish to refrain from life-saving or life-sustaining treatment, the wishes earlier expressed by the patient are usually respected. If it is obvious that the treatment cannot be expected to be of any medical benefit to the patient, one should withhold such treatment already for this reason. It is important that relatives (next of kin) are informed about and understand the decision. In case of disagreement, the wish previously expressed by the patient should be decisive.

1c) If the patient is not capable to make decisions and there is no advance directive, one should try to find out what the patient's values and wishes would have been had the patient been able to express himself/herself, so-called hypothetical will, and these wishes should then be respected. If it is obvious that the treatment cannot be expected to be of any benefit to the patient, one should withhold such treatment also for this reason. It is important that relatives are informed and that there is a consultation before the decision is made. If the prognosis is unclear, life-sustaining treatment should always be initiated. If, at a later stage, continued

treatment turns out not to be of any benefit to the patient, treatment should instead be withdrawn at that stage – see also items 2b and 2c.

1d) If the patient is not capable to make decisions and the patient's wishes and values are unknown and it is unclear whether the treatment is of any benefit to the patient, such treatment is usually initiated and then withdrawn if, at a later stage, it turns out that the treatment is of no benefit to the patient. It is important that relatives are informed about and understand the decision.

All cases in items 1a-d should be offered or given adequate palliative treatment, including palliative sedation.

Withdrawing life-sustaining treatment

2a) If a person is capable to make decisions, he/she himself/herself should be allowed to decide whether life-sustaining treatment (for example ventilator treatment, dialysis, tube-feeding or other forms of supply of nutrition- or hydration) is to be discontinued. This is independent of the prognosis and the remaining time that the patient will live.

2b) If the patient is not capable to make decisions but there is an advance directive, the patient's wishes to discontinue life-sustaining treatment can be respected, independently of whether or not this is of any benefit to the patient. It is important that relatives are informed and that there is a consultation with the relatives before the decision is made. When there is disagreement among the relatives, it should be the patient's previously expressed wishes that apply.

2c) If the patient is not capable to make a decision and there is no advance directive, one should, by asking relatives, try to find out what the patient's values and wishes would have been had the patient been able to express them, i.e. the patient's hypothetical wishes. If it is obvious that continued treatment is of no benefit to the patient, such treatment should also be withdrawn for this reason. It is important that close family are informed and consulted before the decision is made.

In all cases under items 2a-c, the patient should be offered or given adequate palliative treatment including palliative sedation.

Offering palliative treatment and palliative sedation

3a) If a patient who is capable to make decisions is in the final stage of his/her life, either because medical care/the patient has decided to discontinue life-sustaining treatment or due to a progressive degenerative disease for which there is no curative treatment, palliative treatment is given when there is unbearable bodily and/or mental suffering. If this is ineffective according to the patient or a medical assessment, palliative sedation should be offered. The patient should be informed about the possibilities of palliative care and what kind of treatment is considered suitable for the patient in question. In certain cases, the patient is offered to sleep (mild sedation) with regular awakenings, so-called intermittent palliative sedation, but in special cases and at the initiative of the doctor/the team, the patient can also be offered deep continuous palliative sedation. At the request of the patient or at the initiative of the medical service, all other treatments including the supply of nutrition and hydration are then usually withdrawn. If a seriously ill patient addresses the doctor in charge of palliative care and tells him/her that he/she has the intention to refrain from all treatment including the supply of nutrition and hydration and that he/she wants palliative sedation in order to avoid suffering – the doctor should respect the patient's wishes. This procedure can be considered as analogous with the patient who is able to make a decision wishing to discontinue life-support treatment as described in item 2a.

3b) Patients who are not capable to make decisions, but who are considered to suffer both bodily and mentally and where the pain cannot be alleviated in any other way, are usually given continuous palliative sedation while (at the initiative of the medical service) all other care is withdrawn. This kind of palliative sedation is often applied several weeks before the expected death of the patient.

Offering the assistance of a physician prescribing medicine in the case of self-determined end-of-life – so-called physician-assisted suicide

4) If a patient, who is capable of making decisions is in the final stage of life due to a progressive and untreatable disease where predictable bodily or mental suffering that is unbearable can be expected and where the patient declines palliative treatment, wishes to have medicine prescribed that he/she can use to terminate his/her life himself/herself, the doctor in charge of the patient should have the option (but not be obliged), after careful consideration and after review by another doctor, to prescribe such medicine to the patient. This procedure

requires that the patient himself/herself is able to take the medicine and that it does not cause the patient any suffering and pain. Such a procedure is applied in the state of Oregon.

Offering active assistance from a doctor in self-determined end-of-life

5) If a patient who is capable to make decisions is in the final stage of life due to a progressive and untreatable disease where bodily and/or mental suffering can be expected wants to get assistance in ending his/her life in a painless way, a doctor should, after careful consideration, have the possibility to meet such a request. Such a procedure is applied in the Netherlands.

Comments

In the above items 4-5, when we have discussed patients who are able to make a decision, it is implied that

- the patient is in the final stage of life,
- the patient does not suffer from a mental illness that can be treated,
- it is obvious that the measure is taken at the patient's expressive and repeated request, in writing as well as orally,
- more than one doctor participates in the assessment,
- the patient has been subjected to no external pressure,
- the patient is not under age,
- it is evident that the measure does not concern people whose situation in life is characterised by permanent disability.

Even if the situations described above (1-2+3b) are already applied in Swedish health care in practice, this does not mean that they are ethically uncontroversial, particularly not in those cases where a patient who is capable to make decisions wishes to refrain from starting or to discontinue life-sustaining treatment and, at the same time, wants to get assistance with palliative sedation. It is important that the National Board of Health and Welfare revises the wordings in its documentation so that the patient's position in these situations is clarified.

The measures that are discussed in items 3a, 4 and 5 are not currently regulated and do not have any support in law or regulations. Therefore, they are specifically commented on in the following:

In item 3a, it is suggested that patients to an increasing extent be informed about the option of palliative sedation and that the patient himself/herself should be able to decide whether palliative sedation is to be mild and given intermittently or deep and be given continuously. Today, these are questions that are in most cases only determined and decided by the physician in charge of the patient, possibly together with the palliative team where certain criteria for using palliative sedation are complied with.

The criteria should thus be supplemented with guidance from the National Board of Health and Welfare so that the sick patient's right to self-determination is taken into account to a larger extent. Such a patient should also be allowed to take part in the decision, within certain stipulated timeframes, of when a possibly continuous and deep palliative sedation is to be initiated. An argument for this is that patients who are able to make decisions should be treated in the same way as patients who are not able to make decisions, who are troubled and filled with anxiety and who are today subjected to continuous palliative sedation at the physician's initiative.

In analogy with the right of a patient who is capable of decision-making to discontinue life-sustaining treatment (cf items 2a-b), a patient who is in the final stage of life and who wishes to discontinue the supply of nutrition and hydration should be offered mild palliative sedation intermittently or deep continuous palliative sedation if so requested.

A patient should, of course, have the possibility of refraining from palliative care. Palliative care, including palliative sedation, should be considered as an offer and the physician must respect a patient who, for different reasons, considers suffering to be meaningful.

In general, as a physician or medical staff, one should take into account the inferior position, the vulnerability and the dependency of a patient in the final stage of life – thus, one needs to be sensitive to such a patient's wishes and the patient should not need to negotiate for various types of palliative sedation. Doctors and nurses who work with patients that are in the final stage of life due to severe illness or old age have difficult and delicate tasks since the patients are often weak due to their illness and/or age. Thus, one should pay particular attention to the risk of using one's authority and forcing one's own values upon the patient. There are many doctors/nurses and other medical staff in palliative medical care who already today give

patients in the final stage of life a great deal of scope as concerns participation in the decision-making. But there are also indications of there being variations in practice. If such a variation turns out to be large, this creates problems that are related to fairness – patients with similar medical problems should be offered the same care – according to the principle of fairness in the distribution of health care.

Even if palliative care, with certain clarified guidelines, can be expected to be able to fulfil the wishes of many patients in care in the final stage of life, palliative care cannot, even with a change in the criteria for palliative sedation, fulfil all kinds of requirements from seriously ill patients. It is mainly the time perspective that can complicate the issue of continuous deep palliative sedation. For example, a patient with a neurodegenerative illness cannot be offered palliative sedation while he/she is still fully capable to make a decision. In such cases, there might be a need for possibilities for other kinds of self-determined terminations of life such as those described in items 4-5.

Even if there are many arguments for and against items 4-5, there are certain fundamental differences between these two choices of end-of-life that are of importance for the discussion. To prescribe medicine to a seriously ill patient in the final stage of life, that the patient himself/herself can use to choose to shorten his/her suffering by his/her own hand is something different than a doctor actively administering medicine so that the patient dies, even if both cases are at the request of a patient who is able to make decisions. Thus, it is of importance to distinguish between these two situations – which is also reflected in how Swedish physicians consider these actions. The fact that already today, there are physicians who provide medical prescriptions to patients with certain neurodegenerative diseases, for example, does not only indicate a need. The legislators should decide what line of attitude they want to take – if they wish to turn a blind eye, take measures against or allow this activity in ways that can be controlled. We suggest the last course of action, but are, for different reasons, not prepared to accept the possibility that has been outlined in item 5.

Summary

There are two factors that independently point towards the need to revise the patient's right to participate in the decision-making and an increased right to self-determination in care in the final stage of life. One factor concerns the development of knowledge which means that today, patients die from acute illnesses to a smaller extent. Instead, there is a large range of

possibilities for chronically ill individuals to survive/live due to different medical interventions, but at various levels of quality of life. Today, these possibilities for treatment have become so evident that doctors often also assume that patients also want such treatments, even when the patient approaches the end of life, with the risk of abusing the patient's right to take part in the decision and sometimes make the decision himself/herself. The other factor concerns the patient's increasingly stronger position in health care, that is the patient's right to self-determination and to participate in decisions, both when it comes to refusing life-sustaining treatment and the patient's right to get assistance with a painless last period in life.

Today, it is in accordance with good clinical practice to withhold and withdraw life-sustaining treatment in well-defined situations. It also seems to be accepted in practice, under certain well-defined conditions, to offer or apply palliative sedation, intermittently or continuously to such patients. Today, it is not the routine that a patient in the final stage of life is to be given palliative sedation at his/her own request. In this case, the patient's right to self-determination must be respected to a larger extent. Analogously with a patient who is capable of making decisions having the right to refuse life-sustaining treatment, it should be possible to offer palliative sedation to patients who want to discontinue treatment, including the supply of nutrition and hydration. Our opinion is that it should be possible to offer the patients this option.

There is a small number of patients whose wishes cannot be fulfilled by palliative care and where physicians already today prescribe medicine that the patient can use himself/herself to terminate his/her own life. Thus, it should be considered that the legislation be changed so that, after careful consideration, the physician in charge of the patient, together with another physician's assessment, can be given the possibility to, in certain special cases, prescribe medicine that the patients can use themselves to terminate their lives so that they can thus avoid predictable and untreatable suffering.