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Decisions to forego life-sustaining treatment and the duty of documentation

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Abstract *Objective:* To study the current practice of documenting decisions to forego life-sustaining treatment in an intensive care unit (ICU), using the Swedish Medical Records Act as a frame of reference.
Setting: The ICU at Malmoe General Hospital, Sweden.
Materials: The medical records of the first 600 cases treated in the ICU in 1992.
Methods: Analysis of documents and informal observational procedures.
Results: Decisions to forego life-sustaining treatment were documented in the medical records of 34 patients, 17 of whom died in the ICU. In many cases, the treatment is specified, but often it is only rather vaguely described. The main reason for foregoing treatment is poor prognosis. There is no indication that the decisions had been discussed with the patients. In 18 of the 34 medical records, there are notes indicating that relatives were informed about the decision. Notes in most of the 34 medical records imply that joint deliberation took place between the anaesthesiologists in the ICU and the other physician(s) responsible for the treatment of the patient.
Conclusion: The medical records give a fairly accurate picture of the frequency with which such decisions are made at this particular ICU, although the number might be somewhat underestimated. However, the content of the documentation is rather scanty and does not fully satisfy the requirements of the Swedish Medical Records Act. Further studies are needed to warrant any generalization.

Key words Ethics · Documentation · Foregoing life-sustaining treatment · Intensive care unit · Law · Medical record

Introduction

Life-sustaining treatments are sometimes withheld or withdrawn in ICUs [1, 2]. It is generally agreed that this is in the patients' interests. The controversial questions are under what condition this is ethically justified, and when and how the decision should be recorded? Both issues are of particular concern to those working in ICUs, where life-sustaining treatments are a common practice. Although the question of justification has received extensive commentary [3, 4, 5, 6, 7, 8], little attention has been paid to the question of documentation. This article presents the results of a study

of the current documentary practice in a Swedish ICU.

According to the Swedish Medical Records Act of 1986 [9], medical records should contain information about all the implemented and planned interventions essential to the care of the patients and about the reasons for all major interventions. All decisions to withhold or withdraw life-sustaining treatment should therefore be documented. This is also emphasized in the general recommendations of the National Swedish Board of Health and Welfare [10] and the ethical guidelines of the Delegation for Medical Ethics of the Swedish Medical Association [11].

However, Asplund and Britton [12] found that it was very common in Swedish medical wards for the do-not-resuscitate order to be given orally by the physician to the registered nurse. Only 28% of physicians (79 out of 279) stated that they signed their orders, and two strongly advocated that such orders only be given orally.

The survey performed by Asplund and Britton [12] reflects great variations in practice, some falling far short of the requirements of the Medical Records Act [9]. A study by Vincent [13] of such documentations in European ICUs indicates somewhat better, but still inadequate, compliance. However, in this study, the attrition rate was 59% and only 15 Scandinavian physicians responded.

Materials and methods

The medical records of the first 600 cases treated in the ICU at Malmoe General Hospital in 1992 were studied. These 600 records relate to 548 patients, 37 of whom were treated more than once. A total of 1,081 cases were treated in the ICU in 1992. The ICU is not a specialized unit, but intensive care patients with AIDS, burns or chronic respiratory insufficiency were, with few exceptions, treated at the Department of Infectious Diseases; premature children were treated in a special ICU. Neither neurosurgery nor heart surgery was performed at Malmoe General Hospital in 1992.

The medical records examined involve both elective care (37% of cases) and acute care (63% of cases) in the ICU. With the exception of transplantation patients, planned postoperative care in the ICU, as well as planned intensive care for a few other patients, is classified as elective. All other intensive care is classified as acute, including unplanned postoperative intensive care for elective interventions. The median age of patients was 58 years (range 0–93). Women account for 40% of the cases and for 31% of the time devoted to care. The Department of Surgery was responsible for more that half of the patients; all surgical specialities combined, for more than 75%. The median time of treatment was 24 h (range 1–552)

Notes are written in the medical records of all patients almost every day. The anaesthesiologists in the ICU are responsible for writing these notes. In Sweden, anesthesiologists are responsible for the care of patients in the ICU, but other physicians have ultimate responsibility for them. A protocol prepared before the period of examination was used to summarize data from the medical records. All information relating to or bearing on the question of foregoing life-sustaining treatment was identified. As a rule, the first examination of the medical records was made while the patient was still in the ICU. In some cases this was not possible, but with a few exceptions, these cases were examined within a week of discharge from the ICU. All examinations of the records were performed by one of the authors (G.M.). Some statistical data were obtained from the ICU register.

The study was approved by the Research Ethics Committee, and by the heads of the departments of anaesthestiology, surgery and medicine. All anaesthesiologists at the hospital were informed of the study before it started.

What is life-sustaining treatment?

In a Hastings Center Report [14] the term "life-sustaining treatment" is defined as "any medical intervention, technology, procedure or medication that is administered to a patient in order to forestall the moment of death, whether or not the treatment is intended to affect the underlying life-threatening disease(s) or biological processes." This definition is uncontroversial [15], as are the examples of life-sustaining treatment given in the general recommendations of the Swedish National Board of Health and Welfare [10]: mechanical ventilation, extracorporeal oxygenation, assisted circulation, dialysis, pacemaker, pharmacological treatment with vasoactive drugs, diuretics, antibiotics, cytostatic drugs, blood transfusion nutrition and hydration.

Decisions to withhold life-sustaining treatment are made in two different situations. In the first, the decision relates to an actual situation – treatment is to be withheld from a patient who *has* a life-threatening condition. In the second, the decision is hypothetical – to withhold treatment *if* the patient should develop a life-threatening condition. A similar distinction could be made with reference to withdrawing treatment, but in the clinical situation most decisions to withdraw are actual.

Results

In 34 of the 600 medical records (6%), there were notes indicating that decisions to forego life-sustaining treatment had been made. These 34 medical records concern 34 different patients, 18 men and 16 women. Only one record referred to elective care. The median age of the 34 patients was 71 years (range 0–85). Of these 34 patients, 17 died in the ICU and 11 died later on other wards of the hospital; however, six patients left the hospital alive and returned home. For all these six patients, the decision was hypothetical – life-sustaining treatment would be withheld if the patient

should develop a life-threatening condition. During the same period, 15 patients for whom no such decisions had been documented died in the ICU.

Among the 34 medical records, decisions to both withhold and withdraw life-sustaining treatment are indicated, in 20, decisions to withhold such treatment only, in 12, and decisions and to withdraw such treatment only, in two (Table 1). In many cases the treatment is specified, but often the decision to forego life-sustaining treatment is only documented with expressions such as "no new ICU treatment" or "no active treatment" (Table 2). The main reason for withholding or withdrawing treatment is that the prognosis is very poor (Table 3).

Table 1 Number of medical records with documented decisions to withhold or withdraw life-sustaining treatments

Type of life-sustaining treatment	Frequency of treatment	
	To be withheld	To be withdrawn
Resuscitation	17	1
Dialysis	3	3
Mechanical ventilation	10	3[a]
Vasoactive medication	4	4
Blood transfusion	0	0
Nutrition	0	0
Hydration	0	0
Operation	9	0
Unspecified	11	6

[a] In one case, withdrawal of oxygen supplementation; in another, withdrawal if the patient should have spontaneous respiration

Table 2 Unspecific expressions in medical records indicating decisions to withhold or withdraw life-sustaining treatment

Not reasonable with further intervention
No further ICU interventions
ICU treatment should not be continued
Further extraordinary ICU interventions are unrealistic
Further active therapy or investigation is not justified
After this decision, only palliative care
No further active interventions
Care should be limited to fluid and antibiotics
Neither inotrop support nor ventilator
Therapy should primarily be aimed as palliative care
De-escalate active interventions
Terminal care

Table 3 Indications of motives for withholding or withdrawing life-sustaining treatment in medical records

Improvement seems unlikely
Irrespective of interventions the prognosis is very poor
Poor prognosis (and similar expressions)
Interventions do not have any prospect of success (and similar expressions)
Cardiac resuscitation does not have any prospect of success
Mechanical ventilation would only prolong his suffering
The patient is unlikely to survive further cardiac resuscitation
Unlikely that the patient will regain consciousness

According to Swedish law, the patient's autonomy should be respected. The patient has a right to be informed about planned treatment and to refuse treatment, but not to demand a special treatment. There are no indications in the medical records that the decision to forego from life-sustaining treatment had been discussed with the patients or any notes referring to wishes previously expressed by the patients. However, all 34 patients were seriously ill, and many of them comatose, at the time the decision was made. In Sweden, advance directives are not legally binding. None of the patients in the study was known to have given an advance directive.

Although it is not required by Swedish law, it is recommended that relatives be informed. In 18 of the 34 medical records, there are notes indicating that relatives were informed about the decision against life-sustaining treatment. One of the records indicates that the relatives were also involved when the decision was made. Another reports that the relatives wanted the treatment withdrawn. In five of the medical records there are indications of contact with the relatives but no notes implying that they had been informed of the decision to forego life-sustaining treatment. In 7 records the relatives of the patient are not mentioned at all.

Most of the 34 medical records indicate that joint deliberations had been held between the anaesthesiologists in the ICU and the other physician(s) responsible for the treatment of the patient. There are no notes to the effect that the decision was made without consultation and none recording any disagreement. A prerequisite for the proper functioning of an ICU is that other staff members are informed about decisions to forego life-sustaining treatment. The medical records contain no information about how this was done or whether the staff took part in the deliberations. In accordance with Swedish law, the decision is always made by one or more of the responsible physicians.

Discussion

Method

In this study different approaches could have been used, e.g. questionnaires, interviews, observation procedures, and analysis of documents. We chose the latter approach, which offered at least two advantages: it gave us direct access to the documented decisions, and made it possible to corroborate data informally, as one of the authors (G.M.) had frequent contact with the

ICU. This approach strengthened the internal validity of our study.

However, there are also disadvantages. Since only one ICU was studied, the external validity is poor. Generalization requires further studies. It is also possible that information about the study before it started induced some anaesthesiologists to improve compliance with the Medical Records Act [9]. However, this disadvantage is also difficult to avoid with the other approaches.

Results

In six % of the medical records from the ICU in Malmoe, decisions to withhold or withdraw life-sustaining treatment were documented. This frequency conforms with the results of other studies. For example, Smedira et al. [16] found that life support was withheld from one % and withdrawn from five % of the patients in two medical-surgical ICUs in San Fransisco. For somewhat more than half of the patients who died in the ICU in Malmoe (17 of 32), there were documented decisions to forego life-sustaining treatment. Other surveys provide comparable results [17, 18], and thus support the conclusion that the ICU medical records we studied give a fairly accurate picture of the frequency with which such decisions are made. However, our study provides no conclusive evidence. This means that we cannot exclude the possibility that some decisions to forego life-sustaining treatment were made without proper documentation.

The documented decisions are often indicated by means of rather vague expressions. The most frequently made and explicitly formulated recorded decisions are those to withhold resuscitation and to withhold mechanical ventilation. This is not surprising, since such treatment must be initiated immediately if a patient has a cardiac or respiratory arrest. Other life-sustaining treatments, such as dialysis and nutrition, do not require immediate action. In the records examined, no explicit decisions to withhold or withdraw nutrition or hydration are documented. However, there are indications that in some cases nutrition was withheld.

The reasons given for not supplying life-sustaining treatment relate both to quantitative questions (how long the patient will live with or without treatment) and to qualitative ones (the patient's quality of life). The expression "futile care" is often used to indicate such reasons; however, deciding which treatments are futile is notoriously difficult, because "we do not know that recovery is empirically impossible, even if good evidence is available" [19].

Ethics

Is it desirable that the medical records should give a true picture of the frequency with which decisions to forgo life-sustaining treatment are made and of the circumstances? In our opinion, all such decisions should be carefully documented in each patient's medical record. One reason for this is that "good structure increases the likelihood of good process, and good process increases the likelihood of good outcome" [20]. A second one is that this is probably both the simplest and the safest way to inform all members of the medical staff, including the physicians and nurses on call, of the decision. Without such information appropriate care of the patient cannot be ensured. A third reason is that the medical record is a document that makes supervision of important decisions possible and, as such, should include also decisions to forego life-sustaining treatment. Complete and truthfully written medical records are a legal safeguard for patients and their relatives, as well as for health care professionals. Openness is also the best way to secure common trust in the health care system – and to make the system worthy of such trust.

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