

**Decisions to withhold or withdraw life-sustaining
treatment in a Norwegian intensive care unit**



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Introduction

An intensive care unit (ICU) treats the most critically ill patients in the hospital. Over the years advanced therapy and new treatment for critically ill patients have resulted in survival from serious conditions, which previously led to death. With increasing therapeutic possibilities, an increasing incidence of withholding and withdrawal of life support from the critically ill has been shown.¹ ICUs vary in case mix within countries and between countries. For example, some units treat patients from medical, surgical, neurological or other departments, while others treat a combination. ICUs also vary in how often therapy is withheld or withdrawn.²

Withholding or withdrawing life-sustaining treatment represents one of the most difficult decisions that can be made in health care. Recent guidelines from the Norwegian Directorate of Health support professionals in the process of not to start or end life-sustaining therapy. It suggest that limitations in treatment should be considered if such treatment could extend a bothersome death process, extend a life with grave afflictions or prolong a vegetative life.³

Most patients in the ICU are not in a state to make decisions regarding their situation.⁴ About 15% of the patients lack both decision-making capacity and a surrogate decision-maker during the entire ICU stay.⁵ For patients with a very poor prognosis it is considered undesirable to prolong the intensive care treatment. Ethical challenges for how long patients should be offered therapy are raised in earlier studies.^{6,7} However, practices differ between countries and may be due to laws and rules, traditions, religions or ethical views.^{8,9}

Circumstances leading to limitations in therapy in American and European ICUs are partly known. Older age, pre-existing severe medical conditions, emergency surgery, medical admission and cardiopulmonary resuscitation during the past 24 hours prior to admission, are independently associated with the decision to withdraw active treatment. Time to death after

withdrawal of mechanical ventilation varies widely, yet the majority of patients die within 24 hours. There is considerable variation in withdrawal of all active treatment between units, even after accounting for patient factors and differences in size and type of ICU.¹⁰⁻¹³ Some studies from the Nordic countries have investigated how these decisions are made, who is in charge of the decisions and what arguments they are based on.¹⁴⁻¹⁶ This has not been reported for a Norwegian setting.

The aim of this study was to investigate the incidence of withholding or withdrawing therapy, what characterizes the patients with such limitations in their treatment and how these processes are handled during a period of three years in a general ICU in Norway.

Methods

Population

Akershus University Hospital has a catchment population of 460.000 people in Oslo and the county of Akershus. The general ICU in the hospital treats patients from medical, surgical and neurological departments. It has a capacity of nine beds and admits about 430 patients yearly. In this study, we included all 1,287 consecutive patients entering the general ICU at Akershus University Hospital from January 1, 2007 until December 31, 2009.

Data collection and variables

During the stay in the ICU, patients were prospectively assigned to a diagnostic category according to the system of Acute Physiology, Age and Chronic Health Evaluation III (APACHE III) and scored according to Simplified Acute Physiology Score II (SAPS II).^{17,18} Patients under 18 years of age or with lack of information due to a short stay in the ICU did not get a SAPS II. The information was recorded in a local database as a standard routine, together with information on age, sex, reason for admission to the ICU, duration of stay,

invasive mechanical ventilation time, outcome of stay and if therapy was withheld or withdrawn. Withholding therapy is defined as the decision not to start or increase life-sustaining intervention, and withdrawing therapy is the decision to actively stop life-sustaining intervention presently being given.⁸

For the purpose of this study we retrospectively reviewed the computerized medical records of all the patients who had therapy withheld or withdrawn. Arguments for withholding or withdrawing therapy, decision makers, participants in the decision process, type of treatment withheld or withdrawn and the argument for the decision were registered. We used a registration form developed for the purpose. The content and usability of the registration form was tested in a pilot study of 48 medical records, leading to some minor changes to the registration form. When information was unavailable in the medical record, the information was rated as “not documented in medical record”.

Arguments for withholding therapy were rarely documented and therefore not registered. Arguments for withdrawing therapy were classified using the following categories: patient’s request, relative’s request, poor prognosis for acute illness, poor prognosis for chronic illness, poor prognosis of future health, previously physical or mental status, therapy failure, multi-organ failure, age or other argument. In the cases containing several arguments, the most accurate argument interpreted from the medical record was assumed. Comorbidity was scored with Charlson Comorbidity Index, based on information in the medical record at hospital admission. Because of the great variety in patients in a general ICU regarding patient characteristics and outcome, we differentiated between non-operative and post-operative patients according to major disease categories in APACHE III prognostic system.

Data analysis

Descriptive statistics are presented with means (SD), median (25th - 75th percentile) or

frequencies. Groups were compared using the t-test, Mann-Whitney test, chi-square test or Fisher exact test as appropriate. $P < 0.05$ was considered significant. We used Stata version 12 for all analyses (Stata Inc, North Station, TX).

Ethics

The study was presented to the Regional Committee for Medical and Health Research Ethics, but was considered as quality assurance, which did not need further approval (Ref: 2011/950). The Ombudsman at the Data Protection Office, at Akershus University Hospital, accepted the study as quality assurance.

Results

Characteristics of patient population

From 2007 to 2009, 1,287 patients were admitted to the ICU (figure 1), of whom 301 (23%) had treatment withheld or withdrawn. In total, 256 patients had therapy withheld, 130 had therapy withdrawn and 85 patients had therapies both withheld and withdrawn during the stay in the ICU.

Of all patients, 56% were men. At admission ICU, 73% of the patients were considered medical patients, 6% were elective surgery patients, and 21% were emergency surgery patients. Among those who died, there was no difference in Charlson Comorbidity Index between patients with limitations and patients with full active therapy ($p=0.517$).

Patients with limitations in therapy were older, had higher SAPS II and higher estimated mortality than patients with full active therapy, both among non-operative and post-operative patients (table 1). No differences in limitations were shown between males and females. The most common causes for admission ICU were respiratory (25%), cardiovascular (16%), gastrointestinal (14%) and neurological (12%). The distribution of admission

diagnoses differed between the patients with therapy withheld or withdrawn compared with the patients without limitations in therapy, both among post-operative and non-operative patients.

During the stay in the ICU, 16% of the patients died, and 26% died during the overall hospital stay (table 2). Of the patients with limitations in treatment, 237/301 (79%) died before hospital discharge. In total, 11% of the patients with no limitations died. They had a lower in-hospital mortality compared to those with limitations both for post-operative and non-operative patients ($p < 0.001$). No patients survived after having therapy withdrawn. Of the 341 patients who died, 70% had limitations in therapy.

The median length of stay for all patients in the ICU was 2.1 (25th - 75th percentile: 0.8-6.0) days. Among post-operative patients, the patients who had therapy withheld or withdrawn had a longer stay in the ICU than patients without limitations ($p = 0.003$).

In total, 924/1287 (72%) patients received mechanical ventilation. The median duration of mechanical ventilation was 2.0 (25th - 75th percentile: 0.6-6.9) days. The duration of mechanical ventilation was longer for post-operative patients with limitations in treatment, compared with post-operative patients without limitations ($p = 0.002$). Among the non-operative patients, there was no difference in ventilator time according to limitations.

Decision process

Of the patients who had treatment withheld ($n = 256$), 36% had multiple limitations. Cardiopulmonary resuscitation was the most common single treatment withheld. In 22% of the cases, treatment withheld was not documented (table 3).

For the patients who had treatment withdrawn ($n = 130$), the most frequent treatment withdrawn was “All active treatment except for pain relief” (76%), mechanical ventilation (8%) and vasopressors (5%). For 12% of the patients, treatment withdrawn was not

documented. Of the patients with treatment withdrawn, a consultant physician was responsible for the decision in 87% of the cases. In the rest of the cases (13%), a resident was documented as the responsible (table 4). It was documented that another physician was consulted before the decision was made in 43% of the cases. The most frequent argument for withdrawing treatment was “prognosis for acute illness” (44%), multi organ failure (25%) and prognosis for chronic illness (21%). The patient’s age was never used as the only argument for withdrawal of treatment.

Discussion

This study confirms that withholding or withdrawing therapy is common in a general ICU. Of the patients with limitations in therapy, most patients died, and patients with limitations were older and had more severe illnesses than patients with full active therapy. Poor prognosis was the most frequent argument for withholding or withdrawing therapy. A consultant physician made the decisions in most cases. Consultation with another physician was documented in the medical record in almost half of the cases.

Nearly one out of four patients in this study had limitations in treatment during the ICU stay. Previous studies have reported a lower incidence of limitations.^{1,2,8} Among patients who died, a larger proportion of patients had limitations in therapy than in previous European studies.^{2,19} This might be explained by regional differences, or that limitations in intensive care treatment have become more common over the years.¹

Among patients with limitations in treatment, the hospital mortality was about the same as reported by a recent Danish study.¹⁵ This suggests that the practice of withholding or withdrawing therapy is similar in Norwegian and Danish general ICUs.

Factors associated with withholding or withdrawing therapy were older age, higher SAPS II and higher estimated mortality. This corresponds to findings in other studies.^{10,13,14}

Severity scores like SAPS II identify groups of patients at risk of dying at the ICU, but they are unable to estimate the individual risk.²⁰

The most frequent argument for withdrawing treatment was “poor prognosis for acute illness”. “Poor prognosis” was the most common argument in previous studies from North America.^{21,22} Age was not alone used as an argument for withdrawal of treatment, but the patients with limitations were significantly older than the patients with full active therapy. As proposed by other studies, this may indicate that the intensity of treatment is lower in the oldest patients.^{23,24}

In most cases, a consultant physician was documented as responsible for withdrawing therapy. According to the local hospital guidelines, a second physician should take part in the decisions and a physician at the parent ward should always be consulted. In our material this was documented in almost half of the cases. A Norwegian study from 2003, that investigated do not resuscitate orders in a surgical unit, also concluded with a lack of documentation.²⁵

There are some limitations in this study. Information of the decision process is based on retrospective review of computerized medical records, with judgments and interpretation of the text. This may have influenced the assessment of the arguments used to justify the decisions about treatments withheld or withdrawn. At the same time it gives an opportunity to evaluate the documentation process regarding withholding or withdrawing therapy. We recorded ICU and hospital mortality, which may tend to understate the mortality rates, because some patients may have been discharged from the ICU or the hospital in anticipation of death. Therefore, mortality within 30 days may be a more robust endpoint. This study was carried out in a single general ICU in a Norwegian university hospital, and one should be careful about generalization of the results to other institutions with different patient populations or settings.

Intensive care treatment is expensive, and the number of beds is limited. This forces

the physicians to prioritize. In the terminal stage the intention should be to make a dignified process around the end of life. Sometimes constraints are made by the kind of treatment the patients have received before hospital admission or during treatment in other hospital wards before admission to the ICU. In some cases even full active treatment is continued temporarily because of practical circumstances, such as delays in contacts with the patient's closest relatives, even if death is anticipated.

The patients in the ICU are routinely discussed in multidisciplinary meetings with physicians from different specialties. This makes it rather certain that a second physician has been consulted, even if this was not documented in many of the cases. To avoid adverse speculations around these processes, it is important with routines ensuring thoroughly documentation.

We conclude that decisions to withhold or withdraw life-sustaining treatment were common in this Norwegian ICU. Patients with limitations in therapy were older and had more severe illnesses than patients without limitations. Prognosis for acute illness was the most common argument. Consultant physicians were responsible for the decision in most cases, and it was documented that a second physician was consulted in almost half of the cases.

Table 1. Characteristics of 1287 patients in the Intensive Care Unit (ICU) 2007-2009, number (%) unless otherwise stated.

	Non-operative patients *				Post-operative patients *		
	Total	Withheld/ withdrawn	No limitations	p	Withheld/ withdrawn	No limitations	p
N	1287	230	708		71	278	
Age, years, mean ± SD	56.7 ± 20.5	68.6 ± 12.3	51.1 ± 20.4	<0.001	74.5 ± 11.6	56.5 ± 21.1	<0.001
Male sex	723 (56)	131 (57)	399 (56)	0.873	44 (62)	149 (54)	0.205
SAPS II, mean ± SD † ‡	42.3 ± 16.8	56.3 ± 17.3	39.4 ± 14.7	<0.001	49.1 ± 12.6	35.1 ± 14.5	<0.001
Estimated mortality (%), mean ± SD ‡	33.7 ± 26.6	56.1 ± 28.0	28.7 ± 23.4	<0.001	45.7 ± 23.3	23.0 ± 20.6	<0.001
Patient category at admission ICU §				0.377			0.068
Medical	941 (73)	228 (99)	694 (98)		2 (3)	17 (6)	
Elective surgery	76 (6)	0 (0)	8 (1)		8 (11)	60 (22)	
Emergency surgery	270 (21)	2 (1)	6 (1)		61 (86)	201 (72)	
Diagnostic category at admission ICU				<0.001			0.001
Cardiovascular	208 (16)	84 (37)	83 (12)		11 (15)	30 (11)	
Respiratory	326 (25)	65 (28)	202 (29)		11 (15)	48 (17)	
Gastrointestinal	187 (15)	9 (4)	40 (6)		39 (55)	99 (36)	
Neurological	158 (12)	29 (13)	127 (18)		1 (1)	1 (0)	
Trauma	69 (5)	6 (3)	39 (6)		3 (4)	21 (8)	
Sepsis	90 (7)	24 (10)	66 (9)		0 (0)	0 (0)	
Metabolic	123 (10)	5 (2)	118 (17)		0 (0)	0 (0)	
Other	126 (10)	8(3)	33 (5)		6 (8)	79 (28)	

* According to major disease categories in Acute Physiology, Age and Chronic Health Evaluation III (APACHE III) prognostic system.

† Simplified Acute Physiology Score II (SAPS II), theoretical range 0 to 163. Higher scores indicate more severe illness.

‡ Number = 1088, 199 patients were under 18 years of age or did not stay long enough to get a SAPS II and an estimated mortality.

§ Type of admission according to SAPS II.

Table 2. Outcomes of treatment.

	Non-operative patients *				Post-operative patients *		
	Total	Withheld/ withdrawn	No limitations	p	Withheld/ withdrawn	No limitations	p
N	1287	230	708		71	278	
Length of stay in the ICU, days, median (25 th -75 th perc.)	2.1 (0.8-6.0)	2.1 (0.9-6.0)	2.0 (0.6-5.9)	0.196	3.0 (1.7-9.1)	2.0 (0.9-5.1)	0.003
Time on mechanical ventilation, days, median (25 th -75 th perc.) ‡	2.0 (0.6-6.9)	2.0 (0.7-7.3)	2.0 (0.5-6.5)	0.342	3.5 (1.5-11.2)	1.5 (0.5-6.1)	0.002
Died in the ICU, number (%)	208 (16)	122 (53)	34 (5)	<0.001	42 (59)	10 (4)	<0.001
Died before discharge from hospital, number (%)	341 (26)	176 (77)	64 (9)	<0.001	61 (86)	40 (14)	<0.001

* According to major disease categories in Acute Physiology, Age and Chronic Health Evaluation III (APACHE III) prognostic system.

‡ 924 patients received mechanical ventilation, 250 of them had therapy withheld or withdrawn.

Table 3. Frequency of treatment withheld or withdrawn (n = 301), number (%).

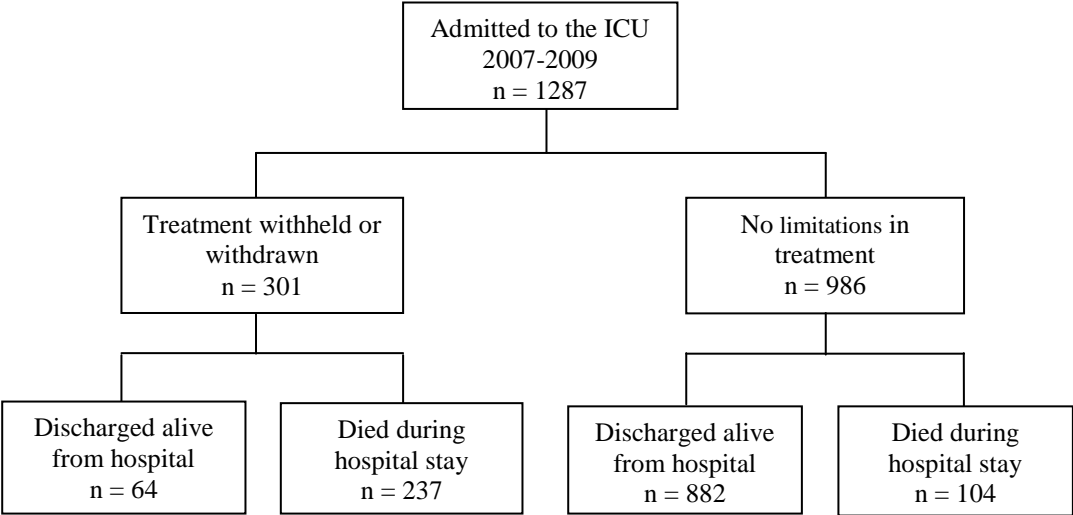
	Treatment withheld*	Treatment withdrawn*
N	256	130
Mechanical ventilation	32 (13)	10 (8)
Vasopressors	6 (2)	6 (5)
All active treatment except for pain relief	-	99 (76)
Cardio pulmonary resuscitation	69 (27)	-
Haemodialysis	2 (1)	-
Multiple limitations	91 (36)	-
Not documented in medical record	56 (22)	15 (12)

* 85 patients had treatment both withheld and withdrawn.

Table 4. Physician responsible for decision to withdraw treatment (n = 130), number (%).

Treatment withdrawn	Total	Consultant	Resident
Mechanical ventilation	10	10 (100)	0 (0)
Vasopressors	6	6 (100)	0 (0)
All medication except for pain relief	99	83 (84)	16 (16)
Not documented in medical record	15	14 (93)	1 (7)
Total	130	113 (87)	17 (13)

Figure 1. Flow chart of patients admitted to the ICU.



References

1. Prendergast TJ, Luce JM. Increasing incidence of withholding and withdrawal of life support from the critically ill. *Am J Respir Crit Care Med* 1997; 155: 15-20.
2. Ferrand E, Robert R, Ingrand P, Lemaire F. Withholding and withdrawal of life support in intensive-care units in France: a prospective survey. *Lancet* 2001; 357: 9-14.
3. Norwegian Directorate of Health. Nasjonal veileder for beslutningsprosesser for begrensning av livsforlengende behandling hos alvorlig syke og døende. Oslo, Norway, 2009.
4. Carlet J, Thijs LG, Antonelli M, Cassell J, Cox P, Hill N, Hinds C, Pimentel JM, Reinhart K, Thompson BT. Challenges in end-of-life care in the ICU. Statement of the 5th International Consensus Conference in Critical Care: Brussels, Belgium, April 2003. *Intensive Care Med* 2004; 30: 770-84.
5. White DB, Curtis JR, Lo B, Luce JM. Decisions to limit life-sustaining treatment for critically ill patients who lack both decision-making capacity and surrogate decision-makers. *Crit Care Med* 2006; 34: 2053-9.
6. Hale C. Recent thinking about end of life issues. *Best Pract Res Clin Anaesthesiol* 2006; 20: 605-17.
7. Siegel MD. End-of-life decision making in the ICU. *Clin Chest Med* 2009; 30: 181-94.
8. Sprung CL, Cohen SL, Sjøkvist P, Baras M, Bulow HH, Hovilehto S, Ledoux D, Lippert A, Maia P, Phelan D, Schobersberger W, Wennberg E, Woodcock T. End-of-life practices in European intensive care units: the Ethicus Study. *JAMA* 2003; 290: 790-7.
9. Reynolds S, Cooper AB, McKneally M. Withdrawing life-sustaining treatment: ethical considerations. *Surg Clin North Am* 2007; 87: 919-36, viii.
10. Wunsch H, Harrison DA, Harvey S, Rowan K. End-of-life decisions: a cohort study of the withdrawal of all active treatment in intensive care units in the United Kingdom. *Intensive Care Med* 2005; 31: 823-31.
11. Cooke CR, Hotchkin DL, Engelberg RA, Rubinson L, Curtis JR. Predictors of time to death after terminal withdrawal of mechanical ventilation in the ICU. *Chest* 2010; 138: 289-97.
12. Ankrom M, Zelesnick L, Barofsky I, Georas S, Finucane TE, Greenough WB, 3rd. Elective discontinuation of life-sustaining mechanical ventilation on a chronic ventilator unit. *J Am Geriatr Soc* 2001; 49: 1549-54.
13. Hall RI, Rocker GM. End-of-life care in the ICU: treatments provided when life support was or was not withdrawn. *Chest* 2000; 118: 1424-30.
14. Nolin T, Andersson R. Withdrawal of medical treatment in the ICU. A cohort study of 318 cases during 1994-2000. *Acta Anaesthesiol Scand* 2003; 47: 501-7.

15. Jensen HI, Ammentorp J, Ording H. Withholding or withdrawing therapy in Danish regional ICUs: frequency, patient characteristics and decision process. *Acta Anaesthesiol Scand* 2011; 55: 344-51.
16. Pettila V, Ala-Kokko T, Varpula T, Laurila J, Hovilehto S, Finnish Sc. On what are our end-of-life decisions based? *Acta Anaesthesiol Scand* 2002; 46: 947-54.
17. Knaus WA, Wagner DP, Draper EA, Zimmerman JE, Bergner M, Bastos PG, Sirio CA, Murphy DJ, Lotring T, Damiano A, et al. The APACHE III prognostic system. Risk prediction of hospital mortality for critically ill hospitalized adults. *Chest* 1991; 100: 1619-36.
18. Le Gall JR, Lemeshow S, Saulnier F. A new Simplified Acute Physiology Score (SAPS II) based on a European/North American multicenter study. *JAMA* 1993; 270: 2957-63.
19. Esteban A, Gordo F, Solsona JF, Alia I, Caballero J, Bouza C, Alcalá-Zamora J, Cook DJ, Sanchez JM, Abizanda R, Miro G, Fernandez Del Cabo MJ, de Miguel E, Santos JA, Balerdi B. Withdrawing and withholding life support in the intensive care unit: a Spanish prospective multi-centre observational study. *Intensive Care Med* 2001; 27: 1744-9.
20. Strand K, Flaatten H. Severity scoring in the ICU: a review. *Acta Anaesthesiol Scand* 2008; 52: 467-78.
21. Keenan SP, Busche KD, Chen LM, McCarthy L, Inman KJ, Sibbald WJ. A retrospective review of a large cohort of patients undergoing the process of withholding or withdrawal of life support. *Crit Care Med* 1997; 25: 1324-31.
22. Smedira NG, Evans BH, Grais LS, Cohen NH, Lo B, Cooke M, Schecter WP, Fink C, Epstein-Jaffe E, May C, et al. Withholding and withdrawal of life support from the critically ill. *New Engl J Med* 1990; 322: 309-15.
23. Reinikainen M, Uusaro A, Niskanen M, Ruokonen E. Intensive care of the elderly in Finland. *Acta Anaesthesiol Scand* 2007; 51: 522-9.
24. Brandberg C, Blomqvist H, Jirwe M. What is the importance of age on treatment of the elderly in the intensive care unit? *Acta Anaesthesiol Scand* 2013 Feb 4. doi:10.1111/aas.12073
25. Steen PA, Dye J, Mjaland O. Do-not-resuscitate orders and cardiopulmonary resuscitation at a Norwegian department of surgery. *Tidsskr Nor Laegeforen* 2003; 123: 3201-2.