Withdrawal of active treatment in intensive care: what is stopped — comparison between belief and practice

Alex J Psirides and Shawn Sturland

ABSTRACT

Objective: To assess the methods of withdrawal of active treatment in intensive care patients and to compare surveyed practice with the beliefs of medical and nursing staff.

Study design: Staff beliefs were assessed prospectively using an anonymous questionnaire. Withdrawal methods were assessed retrospectively by a review of the medical records of 40 consecutive patients who had treatment withdrawn.

Setting: A 14-bed mixed tertiary-referral intensive care unit, February to June 2008.

Main outcome measures: Results of the medical record review and questionnaire were compared.

Results: 11 medical and 45 nursing staff responded (78% and 53% response rate, respectively). Of the 56, 20% believed intravenous maintenance fluids should continue when it is decided to withdraw active treatment; 21% believed ventilation should continue, and approximately 40% believed electrocardiography and pulse oximetry monitoring should continue. Medical staff were more likely than nursing staff to recommend ceasing all treatment and monitoring. Audit of medical records showed that 38 of 40 patients (95%) had ongoing maintenance fluid administration at the time of death. All had respiratory support withdrawn, and one patient had all monitoring removed. Four patients (10%) had clear documentation of their not-for-resuscitation status, and 35 patients (88%) had documentation of a family meeting and the rationale for withdrawal.

Conclusions: These results suggest a wide disparity between belief and practice, with variable documentation regarding end-of-life decision-making and treatment of patients for palliation in the ICU. Several guidelines have been published that might improve end-of-life care. We recommend a standardised approach to improve communication between medical and nursing staff.

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Most deaths in intensive care units in the Western world are expected and follow the decision to withhold or withdraw treatment.[1] A cohort study of ICUs in the United Kingdom found that the decision to withdraw active treatment was made in 9.9% of all ICU patients (including elective admissions), with the median time to death after the decision to withdraw being 2.4 hours; 8% of patients survived more than 24 hours.[2] Although there are regional position statements on withholding and withdrawing treatment,[3] there are few published guidelines on the methods by which this could best be achieved.[4,5] A study of treatment withdrawal in Spanish ICUs reported that the therapeutic interventions most often withdrawn were vasoactive drugs (82%), supplemental oxygen (64%) and mechanical ventilation (57%).[6] In contrast, a French study cited cessation of vasopressors in 25% and supplemental oxygen in 19% of patients in whom treatment was withdrawn,[7] suggesting wide variation in methods of treatment withdrawal.

In our ICU, we observed marked variations in the withdrawal process after initiation by intensive care specialists. This led to uncertainty among the nursing and junior medical staff as to how the process should be carried out. There was also variability in both type and doses of drugs used during the withdrawal process, and inconsistency in documentation of the rationale for withdrawal, including failure to document that the patient was "not for resuscitation". Australian and New Zealand guidelines recommend:

> All decisions regarding the withdrawing or withholding of treatment should be documented in the clinical record … Significant treatments that are to be withheld or withdrawn and those to be continued should be specifically documented.[3]

In the absence of literature suggesting "best practice", we surveyed the opinions of all medical and nursing staff in our ICU as to the "best" method of withdrawal of active treatment. We compared this with the withdrawal process documented in the medical and nursing notes of patients in our ICU.

Methods

The medical and nursing staff of a 14-bed mixed tertiary ICU were asked in June 2008 to complete a simple, anonymous questionnaire relating to a hypothetical patient for whom the decision to withdraw active treatment had been made. Although it has been stated that withholding

and withdrawing treatment are legally and ethically equivalent,[3] this distinction was made to assess attitudes towards cessation of active treatment, rather than the withholding of potential treatment.

Respondents were asked to indicate whether they were medical or nursing staff and the number of years of postgraduate intensive care experience they had accrued. Medical staff comprised registrars (both intensive care and non-intensive care trainees) and vocationally trained intensive care specialists; the nursing staff comprised both staff and charge nurses. All participants were asked to mark each listed treatment or monitoring modality they thought should be discontinued.

The treatment and monitoring modalities are listed in Table 1. They were presented in alphabetical order in the questionnaire to minimise perceived priority bias. An explanatory statement clarified that the term "inotropes" was used to cover all vasoactive substances, including vasoconstrictors and vasodilators. A distinction was made between enoxaparin prophylaxis and active treatment with heparin. A distinction was also made between treatment with the hope of cure or recovery and treatment of a palliative nature, with clarification that only withdrawal of the former was the subject of the questionnaire.

The second part of the questionnaire asked, "What medication(s) should be started or continued once the decision to withdraw treatment has been made?" and "What do you think should be documented in the notes before withdrawal?"

To assess current practice, the medical records of 40 consecutive patients to have active treatment withdrawn in the ICU were audited retrospectively, working backwards from the day before the questionnaire was distributed. Records of all patients to die in the ICU were obtained; if the death was not due to withdrawal of active treatment (death was unexpected or due to limitation of treatment), the patient was excluded, and further records were obtained retrospectively. Each patient record was audited to determine the documentation surrounding the decision to withdraw treatment. The information obtained included documentation of resuscitation status, the drugs prescribed and administered after the decision was made to withdraw treatment, and the treatment and monitoring in place up to the time of death. These were taken from the 24-hour nursing observation chart, the prescription chart, and the medical and nursing records.

The outcome of the questionnaires ("belief") was compared with the findings from the records ("practice").

As the study consisted of a voluntary staff questionnaire and a retrospective review of patient notes with no intervention, ethics approval was not considered necessary and thus was not sought.

Table 1. Responses to questionnaire about ceasing treatment and monitoring modalities during withdrawal of active treatment

Treatment or monitoring modality	No. of staff recommending cessation		
	Medical ($n = 11$)	Nursing ($n = 45$)	Total ($n = 56$)
Enoxaparin prophylaxis	11 (100%)	45 (100%)	56 (100%)
Dialysis	11 (100%)	44 (98%)	55 (98%)
Heparin	11 (100%)	43 (96%)	54 (96%)
Antibiotics	11 (100%)	42 (93%)	53 (95%)
Central venous line	11 (100%)	42 (93%)	53 (95%)
Insulin	11 (100%)	42 (93%)	53 (95%)
Total parenteral nutrition	11 (100%)	41 (91%)	52 (93%)
Inotropes	10 (91%)	41 (91%)	51 (91%)
Nasogastric feed	10 (91%)	39 (87%)	49 (88%)
Arterial line	10 (91%)	37 (83%)	47 (84%)
Intravenous maintenance fluids	10 (91%)	35 (63%)	45 (80%)
Pacing	10 (91%)	34 (76%)	44 (79%)
Ventilation (invasive or non-invasive)	9 (82%)	35 (63%)	44 (79%)
Electrocardiography	7 (64%)	28 (62%)	35 (63%)
Pulse oximetry	10 (91%)	22 (49%)	32 (57%)

Results

Questionnaire

The results of the questionnaire are shown in Table 1. We received 56 completed questionnaires, 11 from medical staff and 45 from nursing staff, representing a response rate of 78% for medical staff and 53% for nursing staff.

Five doctors (45%) and 14 nurses (31%) recommended cessation of all the modalities listed. Most staff preferred morphine as the first-line treatment in palliation (66% of responses), with hyoscine (29%) and midazolam (21%) following in preference. Other medications included "antiemetics" and propofol.

With regard to appropriate documentation, all the medical staff stated that the reason for withdrawal, the concept of futility and those involved in the decision-making process should be clearly stated in the patient notes. Additional suggestions included whether organ donation (if appropriate) had been discussed, whether coronial notification should be sought, and documentation of the views of the family on stopping active treatment.

The comments made by nursing staff reflected a more practically oriented, patient-centred approach. The most

common request was for clear documentation regarding a not-for-resuscitation statement, and for explicit planning as to what should be stopped and what should continue or be initiated. Other suggestions included the naming of who was present at the family meeting and, in concurrence with medical staff, what their response was to stopping active treatment.

Audit of medical notes

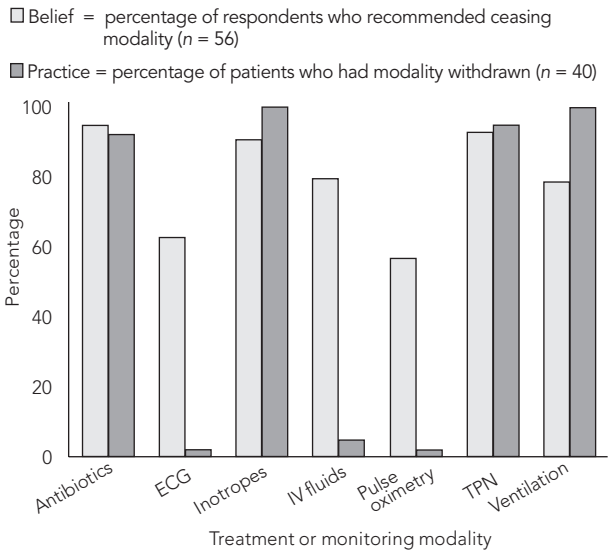
Forty patients had active treatment withdrawn in the ICU over the period February to June 2008. All patients had respiratory support withdrawn, with no patients remaining intubated or receiving non-invasive ventilation at the time of death. Thirty-eight of the 40 patients (95%) had a record of ongoing intravenous administration of maintenance fluids until death, with two (5%) having total parenteral nutrition continued. One patient (3%) had all electrocardiographic and pulse oximetry monitoring removed, with the remaining 39 having observations (heart rate and rhythm, oxygen saturation and blood pressure) recorded until death. All 40 patients had inotropes ceased. Five (13%) had urine output recorded hourly, and three (8%) had antibiotics administered during the treatment withdrawal process.

Documentation of the rationale behind withdrawal and the subsequent management plan varied. The records of 35 patients (88%) contained details of a family meeting and the rationale for withdrawal. One patient who had been "brought to the ICU to die" had no documentation regarding intensive care management at all. An explicit not-for-resuscitation statement was recorded in four patient records (10%). Any notes of the final family meeting referred only to "the family", without listing specific members who had attended.

Statements regarding the rationale for withdrawal mostly referred to futility of continued treatment. A single note explicitly stated that "all ventilation, inotropes, monitoring and fluids should be ceased", whereas most statements referred to "planned withdrawal of supportive treatment" or "discontinue extraordinary life support measures", without listing the exact means by which this should occur. Most statements were variations on the phrase "for withdrawal of treatment". With regard to palliative medication, specific drugs were referred to for only three patients (8%): for example, "for morphine if any evidence of distress" or "for fentanyl infusion". The most frequently charted palliative medications were opiates (morphine and fentanyl). Four patients (10%) did not have their premorbid medications crossed through on the medication chart.

Figure 1 compares results from the questionnaire (belief) and note audit (practice).

Figure 1. Comparison of belief and practice about ceasing treatment and monitoring modalities during withdrawal of active treatment



ECG = electrocardiography. IV = intravenous.
TPN = total parenteral nutrition.

Discussion

These results highlight the differences in belief about active treatment withdrawal in the ICU between medical and nursing staff and marked inconsistencies between belief and practice. The latter may reflect inadequate communication of the wishes of medical staff (for example, removal of all monitoring) to the nursing staff who actually undertake end-of-life care. The greatest disparity in belief and practice was seen for discontinuation of fluids, electrocardiography and pulse oximetry monitoring. The reluctance to stop the latter two procedures appears in keeping with the highly monitored environment in which intensive care staff work, where even the dying process is electronically observed. This contrasts with other areas of the hospital and the community, where death, by necessity, is monitored and finalised clinically rather than by reliance on an electronic display. Continuing observations, such as hourly urine output and oxygen saturation, are of no benefit to a dying patient.

Despite the belief of 20% of respondents that dying patients should continue to receive intravenous fluids, there is little evidence in the intensive care literature supporting either their continuation or cessation. Intravenous fluid administration is usually avoided in palliative care, with oral or subcutaneous routes preferred, and fluid administration has been shown to play a minimal role in providing comfort to terminally ill patients.[8] This mode of therapy showed the

largest gap between belief and practice. Internal inconsistencies were seen, with 13% more respondents wishing to stop total parenteral nutrition than intravenous fluids, despite both serving essentially the same purpose. Stopping ventilation (and extubating the patient) at withdrawal of active treatment is established practice in our ICU (hence the 100% prevalence), as is stopping all inotropes, yet this conflicted with the belief of 21% of respondents (for ventilation) and 9% (for inotropes) that these should be continued. Published data on the prevalence of extubation at withdrawal are scarce, although a 1994 survey of critical care physicians found that 13% of doctors used this method exclusively;[9] the same study also cited a 6% rate of use of paralytic agents in combination with extubation or terminal weaning, a practice that is not carried out in our ICU.

Comparing the groups surveyed, medical staff were more likely to recommend stopping all monitoring and treatment modalities, with 100% agreement for seven out of the 15 modalities listed. Nursing staff showed complete agreement only on cessation of enoxaparin prophylaxis; this was also the only modality that both medical and nursing staff all agreed should be stopped. The more senior medical staff (as determined by years of experience) were more likely to recommend stopping everything; for nursing staff, there appeared no correlation, but the absolute numbers of both groups were small.

With regard to sources of error, the presence of documented observations on a nursing chart has been taken to indicate that monitoring continued, when it may actually have ceased. Requests for cessation of treatment or monitoring or the beginning of new therapies may have been passed on verbally rather than documented in the medical records. This is less likely to apply to medications (especially opiates), which require an explicit prescription.

Failure to stop medications that arguably are of no benefit to a dying patient, such as antibiotics, reflects an oversight on the part of the physician withdrawing therapy and a possible reluctance on the part of the administering nurse to withhold medication that is still prescribed. Both reflect a lack of clarity in the rationale for withdrawal and lack of communication of the means by which this is to be achieved. Staff opinions as to which medication to commence included opiates (as morphine) three times more often than benzodiazepines (as midazolam) as first-line treatment. This contradicts the advice of several published guidelines (including the Liverpool Care Pathway[10]), which recommend benzodiazepines as first-line treatment for "terminal restlessness and agitation". This may reflect the liberal use of morphine in our ICU, both as a sedative agent and as the first-preference analgesic, but may also arise from the possibly erroneous interpretation of agitation as being caused by pain. The Liverpool Care Pathway contains explicit recommendations for management of nausea, pain, respiratory secretions, delirium and shortness of breath, all of which may present in varying degrees in palliative ICU patients. As such, rather than a single-medication approach to multiple symptoms, it would be preferable to use individual targeted therapies that would have greater benefit for the patient. This would also be more consistent with the principles applied to non-palliative ICU patients.

With regard to medical documentation, the observed 10% frequency of recording not-for-resuscitation status is comparable with the published figure of 8% for intensive care in Italy, but contrasts with a high of 91% in the Netherlands,[11] although the latter study did not specifically refer to patients in whom treatment had been withdrawn, who would be expected to have a higher rate of documentation. The low observed rates of documentation of the individuals involved in final family meetings, and of the treatments to be ceased are inconsistent with published Australian and New Zealand professional guidelines.[3,12]

The observed gap between belief and practice in medicine has been termed the "quality chasm" and recognised in intensive care since the 1990s.[13] It is not unique to this area of medicine, although some authors argue that ICUs are ideal places to test new approaches in "implementation science" — the adoption of best practice at the bedside.[13] In an area where best practice is not clear, narrowing this gap seems difficult. Efforts to standardise treatment withdrawal using protocols have been studied in other acute care areas, such as emergency departments.[14] Where palliative care overlaps with intensive care, guidelines for methods of withdrawal have also been published,[5] although comprehensive guidelines such as the Liverpool Care Pathway[10] are few. This paucity of evidence may account for some of the disparities found in our survey between the beliefs of medical and nursing staff.

A standardised documented approach to the withdrawal of treatment in dying patients would improve communication between medical and nursing staff. A more predictable and consistent approach between medical staff may also lead to improved care of the dying patient. We hope that our study will lead to the establishment of withdrawal guidelines for our ICU to address the issues identified.

Author details

Alex J Psirides, Senior Fellow, Intensive Care Medicine[1,2]
Shawn Sturland, Specialist, Intensive Care Medicine[1]
1 Intensive Care Unit, Wellington Hospital, Wellington, New Zealand.
2 Intensive Care Unit, Alfred Hospital, Melbourne, VIC (current address).
Correspondence: alex@angelic.com

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