

A pilot audit of the process of end-of-life decision-making in the intensive care unit

Martina Zib and Peter Saul

Withdrawal of potentially life-prolonging treatments is a common procedure in most intensive care units.¹ Vignette studies have suggested there is considerable variability in approach between and within ICUs.² Quality improvement activities have been hampered by the absence of a clear sense of “best practice” in this complex area. Recent guidelines issued by a variety of authoritative bodies provide, for the first time, elements of best practice on which quality improvement cycles could be based.³⁻⁵

A consensus conference of intensivists held in Brussels in 2003 considered treatment withdrawal to be a “shared decision”, with responsibility shared between the caregiver team and the patient surrogates.³ They envisaged the reaching of consensus between the parties as a dynamic process and strongly emphasised communication as a way of achieving that consensus.

In the same year, the Australian and New Zealand Intensive Care Society (ANZICS) published guidelines on withholding and withdrawing treatment.⁴ The logical first step of those guidelines was the attainment of medical consensus. Once medical consensus had been reached, the concurrence of patient surrogates was sought. The absence of dissent from patient surrogates was taken to signify overall consensus. The ANZICS guidelines conclude with a recommendation for the development and implementation of local guidelines regarding end-of-life (EOL) management.

That recommendation is being taken up. In 2005, New South Wales Health released *Guidelines for end-of-life care and decision-making*.⁵ The document provides a detailed, practical guide to the process of achieving consensus. Process factors such as communication and disclosure are highlighted. The importance of documentation, both as best practice and also as a potential recourse in the event of conflict, is emphasised. The guidelines conclude with a recommendation for the development of local policy.

Accordingly, the current audit was conceived as a pilot study with two aims. The first aim was to gather descriptive data about practice in our ICU. The second aim was to gather information upon which to build an audit tool for use in quality improvement activities. Specifically, answers to the following questions were sought:

- Could meaningful information be gathered about the recommended elements of a best practice approach to treatment withdrawal?
- Is it possible to construct a practical ongoing audit tool?

ABSTRACT

Background: Withdrawal of potentially life-prolonging treatments is a common procedure in most intensive care units. Until recently, quality improvement activities have been hampered by the absence of a clear sense of “best practice” in this complex area.

Objective: This pilot audit addresses the feasibility of developing an end-of-life (EOL) decision-making audit and quality improvement tool and applying it in the intensive care setting.

Methods: Between November 2005 and April 2006, treatment was withdrawn from 47 patients in our ICU. Their charts were audited, and a structured interview was conducted with the intensivist who documented the decision. We defined treatment withdrawal as the cessation of mechanical ventilation and all other forms of life support in the anticipation of the patient’s death.

Results: 55% of ICU deaths were the result of treatment withdrawal. Overwhelmingly, treatment failure or futility was the reason cited for withdrawal. There were no cases of conflict between the medical team and the patient’s family. The level of confidence among intensivists about EOL decision-making was high. Consultation with ICU colleagues was rated as the most helpful factor in decision-making. Intensivists wished for earlier and more active support from the admitting medical officers in decision-making. Strong support for advance planning and for audit of EOL decision-making was highlighted.

Conclusions: A current ICU quality improvement review lists EOL management as a possible audit item (Curtis et al. *Crit Care Med* 2006; 34: 211). Our study demonstrated the feasibility of developing a quality improvement tool for EOL decision-making and applying it in the intensive care setting. As evidence about the process of EOL decision-making accumulates, that process should become a component of quality assurance audit in intensive care.

Crit Care Resusc 2007; 9: 213–218

- Would audit be acceptable to senior medical staff?

The elements of best practice are the attainment of consensus — first medical consensus and then a management plan agreed between the medical teams and patient surrogates — respect for patient wishes, appropriate

Table 1. Characteristics of 47 audited patients

Characteristic	No. of cases
Clinical condition	
Intracranial haemorrhage	23 (49%)
Traumatic brain injury	3 (6%)
Inotrope-resistant shock with multi-organ failure	20 (43%)
Inability to wean from ventilation in the context of severe chronic lung disease	1 (2%)
Timing of withdrawal after admission to ICU	
< 24 hours	8 (17%)
1–3 days	11 (23%)
3–7 days	26 (56%)
> 1 week	2 (4%)
Reason for treatment withdrawal	
Futility	42 (90%)
Quality of life	4 (8%)
Patient wish	1 (2%)

involvement of patient surrogates, the resolution of conflict if it arises, thorough documentation and a commitment to ongoing audit.⁵

Methods

We defined treatment withdrawal as the cessation of mechanical ventilation and all forms of life support in the anticipation of the patient's death. The audit sample comprised all patients who had treatment withdrawn in our ICU during the 6-month period, November 2005 to April 2006.

After treatment withdrawal, patient charts were audited with a focus on documentation of the process of treatment withdrawal. Best practice recommendations⁵ clearly state the importance of thoroughly documenting the medical facts leading to the decision to withdraw treatment, the people involved, the patient's wishes — if known — and the goals and details of treatment. We aimed to compare the standard of documentation in our unit with these recommendations.

A structured interview was conducted with the intensivist who documented the withdrawal decision within 1 week of the decision. The aim was to obtain information about intensivists' perspectives regarding EOL decision-making.

The initial part of the interview focused on specific questions, and the latter part allowed open-ended responses and discussion. Overall, the interviews took an average of 20 minutes. All 15 intensivists and provisional fellows in our ICU took part. The interviews were recorded on a structured sheet. Verbal consent was obtained for the interview.

The interview questions were designed to gather information about intensivists' reasons for withdrawing treatment, the process factors involved in reaching medical and overall consensus, and intensivist confidence in, and satisfaction with, EOL decision-making in the ICU. With a view to constructing an ongoing audit tool, we also sought intensivists' opinion regarding audit. Information about the practical aspects of EOL decision-making, particularly an estimate of the time involved in reaching consensus, was also sought. The interview concluded with an EOL decision-making "wish list" designed to provide intensivists with an opportunity to volunteer their opinions of difficulties in EOL decision-making.

The descriptive data were collated under the subheadings of the recommended elements of best practice.

Results

Over the 6-month audit period, 47 patients had all potentially life-prolonging treatments withdrawn. These comprised 55% of ICU deaths in the period.

Characteristics of the 47 patients are summarised in Table 1. In 42 patients (89%), the grounds for treatment withdrawal were cited as futility. Intensivists appeared to define futility either as an obvious failure of a trial of maximum treatment or as a consensus view, shared by the medical team and patient surrogates, that the patient would not survive.

Quality of life was the reason cited in four cases (8%). Patient wish was the reason for one treatment withdrawal — an elderly man with chronic respiratory failure unable to be weaned from ventilation. While survival was not seen as impossible, in these cases the burdens of treatment were seen as outweighing the benefits.

Medical consensus

Table 2 summarises the consensus-building process. The audit focused on the supervising intensivist. Information about the involvement of social workers or chaplains was not recorded, although we recognise that their input is often a vital part of the process.

The number of occasions on which nursing staff were documented as being present at family meetings was recorded, as was the number of times the intensivist rated nursing staff as active in decision-making. Nurses were documented as being present at 40 family discussions (85%). In no instance were nursing staff involved in the initiation of EOL discussions, and in only two cases (6%) were nurses rated as being active in decision-making. The reason for these results is not clear and could be addressed by future research.

The admitting medical officer (AMO) discussed the decision to withdraw treatment with the ICU team in 45 cases

Table 2. Summary of consensus-building approach in 47 cases of treatment withdrawal

Feature of consensus-building	No. of cases
Respect for patient wishes	
Advance directive	0
Documentation of patient wish	6 (13%)
Prior EOL discussions held	0
Person responsible identified and documented	21 (45%)
Family involvement	
Involved in EOL discussions	47 (100%)
Documentation of members involved	12 (25%)
Conflict within family	0
Conflict between family and medical teams	0
Number of discussions with family	
1	5 (11%)
2	11 (24%)
3	18 (38%)
> 3	13 (27%)
Admitting medical officer involvement	
Documented involvement	20 (43%)
Discussion with ICU team	45 (96%)
Discussion with family	35 (75%)
Attendance at one or more family meetings	13 (27%)
Time invested by intensivist	
1 hour	13 (27%)
2 hours	15 (33%)
3 hours	7 (15%)
> 3 hours	12 (25%)
EOL = end-of-life. ♦	

(96%). In 35 cases (75%), the AMO discussed the decision with the patient's family or surrogates, and in 13 cases (27%) attended one or more of the family meetings. The AMO documented his or her involvement in 20 cases (43%). Most intensivists and provisional fellows wished for earlier and more active AMO support. EOL management planning by the AMO before the patient's condition deteriorated, particularly in patients with chronic conditions and those with a poor prognosis, featured on 39 (82%) of the intensivists' wish lists.

In 30 cases (64%), more than one intensivist was involved in the process of reaching consensus. This occurred, with about equal frequency, in either of two ways. In the first, care of the ICU was handed over from one intensivist to another, and accordingly the second intensivist concluded the EOL discussions that had been commenced by their predecessor. Alternatively, the supervising intensivist discussed the case with a colleague. Formal request for a second opinion as a

means of conflict resolution did not occur in our audit. Intensivists rated consultation with ICU colleagues as the single most helpful factor in decision-making. Typically, the cases in which consultation with an ICU colleague was not sought were those that either occurred suddenly out of hours or those that were considered very clear, such as a catastrophic intracranial haemorrhage.

Intensivists' confidence in decision-making was high. In 45 cases (96%), the intensivist was confident about the salient medical facts, the family and AMO support, and the process of treatment withdrawal. In two cases (5%), the intensivist was uncertain about family and/or AMO support. In only one case (2%) was the intensivist uncertain about the medical facts informing the decision to withdraw treatment. We did not specifically ask about the reasons for intensivists' confidence. However, those who volunteered a reason spoke about allowing a sufficient treatment trial or about the severity of physiological derangement in the patient.

All 15 intensivists and provisional fellows in our ICU were involved in EOL decision-making. In 34 cases (73%), the intensivist felt that they took responsibility for the decision, while in 13 cases (27%) they felt that the AMO took responsibility for the decision.

The discussion about treatment withdrawal was initiated by the intensivist in 30 (64%) of the audited cases, by the AMO in 16 (34%) cases, and by the family in the one remaining case. The mean time from the first suggestion of treatment withdrawal to withdrawal was 4.9 days. The median was 2.6 days.

We recorded the time invested in EOL discussions, as estimated by the intensivist who documented the treatment withdrawal decision. In 34 cases (73%), this was 2 or more hours, and in 25% of cases it was 4 or more hours. These figures are probably an underestimate as more than one intensivist was often involved in the care of a patient.

Respect for patient wishes

In none of the audited cases was an advance directive available. In 28 of the intensivist interviews (60%), access to an advance directive or equivalent was listed on their EOL decision-making wish list. Similarly, there were no cases in which documented discussions about EOL management were held with the patient before they became too ill to participate. A surrogate "person responsible" was identified and documented in 21 cases (45%). For six patients (13%), there was documentation of what was thought to be their wish, as reported by the patient surrogate.

Appropriate involvement of surrogates

In all the audited cases, there was active family involvement, but documentation of this involvement was often inadequate. The people present at family discussions were

Table 3. Summary of intensivists' "wish lists" for end-of-life (EOL) decision-making

Intensivist wish	No. of interviews in which wish was volunteered (n=47)
Consideration of EOL decisions by treating physicians/AMO team before patient deterioration	38 (81%)
AMO insight into the process of EOL decision-making, including AMO involvement in EOL discussions with patient/family	32 (68%)
Advance directive or equivalent: "a definite idea of what the patient would have wanted"	28 (60%)
More time: intensivists felt they either had to rush EOL decision-making due to time constraints or neglected other activity in the ICU while managing EOL	21 (45%)
EOL planning by treating physicians for patients with chronic or progressive disease	14 (30%)
Legal aspects: more "clarity" regarding legal repercussions in cases of conflict	7 (15%)
Avenue for mediation if intensivists disagree about the appropriateness of an EOL decision	2 (5%)

AMO = admitting medical officer.



documented in 12 cases (25%), and a "person responsible", as agreed by the family and treating team, was identified and documented in 21 cases (45%).

Resolution of conflict

During the audit period, there were no instances of conflict between family members sufficient to impair the consensus-reaching process, and no instances of conflict between the medical teams and the family.

All intensivists expressed unease about handling a case of conflict. In 44 interviews (93%), intensivists thought that, in the event of conflict, a second opinion would be helpful for resolution. In three interviews (7%), intensivists thought that a trained mediator would be helpful. None rated an ethics committee or chaplaincy as a helpful form of mediation.

Thorough documentation

The medical facts leading to the decision to withdraw treatment were documented in all cases. However, documentation of patient wishes, of the decision-making process and of the people involved in discussions was incomplete. Patient wishes regarding EOL care were documented in six cases (13%), consensus within the treating teams in 31 cases (66%), and consensus within the family in 23 cases (49%). AMOs documented their involvement in 20 cases (43%), while the people involved in family discussions were documented in 12 cases (25%).

Ongoing audit

Ongoing quality improvement activities were seen as being important to ICU practice and morale. Specific audit of EOL decision-making was supported unanimously. That support was overwhelmingly for internal, as opposed to external, audit. We defined internal audit as audit carried out within the unit by members of the unit. Internal audit was

supported by intensivists in 41 (87%) of the interviews. External audit was defined as audit conducted by independent auditors from outside the unit. External audit was supported by intensivists in six (13%) of the interviews. Concerns expressed about external audit included lack of familiarity of external auditors with individual units, and the perception that EOL management would then be tailored to suit an external process rather than to provide the best care for individual patients and their families.

Intensivists' wish lists

The aim of the wish list was to provide intensivists with an opportunity to volunteer difficulties that they encounter in EOL decision-making. The list is summarised in Table 3. Most striking was the need for more appropriate and earlier AMO involvement. Intensivists reported frustration at being the first doctor, often despite prolonged medical treatment, to discuss a poor prognosis with the patient or patient surrogates.

Discussion

The findings of our study add to a small but growing body of evidence, mostly descriptive, regarding EOL decision-making in ICUs. Available literature highlights the lack of consistency in EOL decision-making between countries, between ICUs and between individual intensivists.^{2,6} Therefore, practice in our ICU may differ from that in other ICUs in Australia. It certainly differs from the practice of ICUs in other parts of the world.³

We report that treatment failure or futility was overwhelmingly the reason cited for treatment withdrawal. This is consistent with published reports that probability of survival and patient wish were the two most important criteria for withholding or withdrawing treatment.⁷ In the recently published Irish subset of the Ethicus Study, 68% of

patients had life-sustaining treatment limited because of lack of response to maximum therapy.⁸ The Canadian Level of Care Study used the need for inotropes and vasopressors as a measure of poor treatment response, and found that this need was significantly associated with withdrawal of mechanical ventilation.⁹

While a precise theoretical definition of futility remains elusive, an operational definition usually centres on a fair and transparent process that includes as many stakeholders as possible. Indeed, NSW Health's *Guidelines for end-of-life care and decision-making*⁵ can be seen as an attempt to define futility as a matter of process. Judgements about quality of life may arise as part of this process and are, perhaps, a subset of the overall concept of futility.

The Level of Care Study also reported that, "rather than age or severity of illness and organ dysfunction, the strongest determinant of the withdrawal of ventilation in critically ill patients was the physician's perception that the patient preferred not to use life support".⁹ However, in that study, as in our audit, patient preference was seldom recorded.⁹

No written advance directives were available for our patients, and there were no documented instances of EOL discussions being held with patients before they became too ill to participate. The two changes to EOL management most "wished for" by intensivists were EOL planning by the AMO team before the patient's condition deteriorated, and access to a patient advance directive or equivalent. Consistent with this finding, recent research regarding cardiopulmonary resuscitation (CPR) decision-making found that few patients had discussed CPR with their physicians, while most had poor knowledge of what CPR involved.¹⁰

These data imply that early discussion between doctors and patients and between patients and their families about EOL decisions would be of benefit. For patients with chronic conditions, who may increasingly be considered for critical care,¹⁰ the treating doctor is in the best position to discuss this care and EOL management with both the patient and family before the patient becomes critically ill.

The time investment in EOL decision-making was significant, and a proportion of intensivists felt that time pressures affected either their involvement in EOL decision-making or the care they gave to the remainder of the ICU. Early discussion about EOL management before ICU admission would potentially decrease the time needed to reach a consensus decision.

Notable among our results was the absence of conflict. Cases of conflict between family and medical staff regarding EOL decisions are probably not common, although few figures have been published. When conflict does occur, it is emotive, costly and often very public. Concerns have been raised about communication between ICU staff and families.³ Additionally, there have been suggestions that conflict

requiring third-party intervention may become more common.¹¹

We are unable to account for the lack of perceived conflict in our audit. Time from first suggestion of treatment withdrawal to actual withdrawal was similar in our audit (median, 2.6 days) to the Irish Ethicus cohort (median, 2.9 days). Three or more family discussions were held in 31 (65%) of the audited cases. The lack of conflict we observed may relate to the repetition of discussions with family or to the demographic characteristics of our area.

Documentation in our ICU was inadequate when compared with best practice guidelines.⁵ Clear communication is one important function of documentation in medical records. Another function, particularly relevant in EOL decision-making, is transparency and accountability.⁵

Study limitations and strengths

Our study had several limitations. It was an observational study, in a single ICU over a 6-month period, and the results are purely descriptive. While recruitment of patients was prospective, data collection was retrospective. For these reasons, accurate data about some potentially important questions, such as the total time invested in reaching consensus, could not be gathered. An ongoing audit tool that is completed during the process of EOL decision-making might address some of these limitations.

Most publications regarding EOL decision-making examine withholding as well as withdrawal of treatment, encompassing a broad range of clinical decisions. Our definition of treatment withdrawal was the cessation of mechanical ventilation and all forms of life support in the anticipation of the patient's death. This definition obviously selects a more specific subgroup of patients, which is a strength of our study.

The interview component of our study allowed us to gather information about intensivists' perspectives that would not have been available from an audit of medical records. Information gathered from the decision-making wish list (Table 3) has, to our knowledge, not been documented previously.

Ongoing audit and quality improvement

EOL decision-making is a complex area and a potentially difficult target for quality improvement measures. However, a current ICU quality improvement review lists EOL management as a possible audit item.¹² Our pilot audit demonstrated strong support for ongoing audit and quality improvement.

From this pilot audit, certain features of an audit tool appear to be practical. It could be chart- or form-based and should be clear and concise. A checklist format is practical and would serve as an aid to memory during the process of

reaching consensus. Information related to best practice should be recorded:

- the attainment of consensus — first medical consensus, and then a management plan agreed between the medical teams and patient surrogates;
- respect for patient wishes;
- appropriate involvement of patient surrogates;
- the resolution of conflict if it arises;
- thorough documentation; and
- a commitment to ongoing audit.⁵

Information regarding the practical aspects of EOL decision-making and the application of audit could also be recorded, particularly resource utilisation and time investment.

Information gathered could be used to improve practice within ICUs, and also to compare process factors between units, in a manner similar to the outcome measures in databases such as the ANZICS database of demographic characteristics and outcomes of intensive care patients.

We conclude that audit of EOL decision-making is warranted, practical and acceptable to intensivists. We contend that an audit process could document adherence to best practice, and could pre-empt personal and legal conflict.

Author details

Martina Zib, Postgraduate Fellow in Intensive Care

Peter Saul, Intensive Care Specialist

Department of Anaesthesia and Intensive Care, John Hunter Hospital, Newcastle, NSW.

Correspondence: mzib@bigpond.com

References

- 1 Prendergast T, Luce J. Increasing incidence of withholding and withdrawal of life support from the critically ill. *Am J Respir Crit Care Med* 1997; 155: 15-20.
- 2 Cook D, Guyatt G, Jaeschke R, et al. Determinants in Canadian health care workers of the decision to withdraw life support from the critically ill. *JAMA* 1995; 273: 703-8.
- 3 Thompson B, Cox P, Antonelli M, et al. Challenges in end-of-life care in the ICU: statement of the 5th International Consensus Conference in Critical Care: Brussels, Belgium, April 2003: executive summary. *Crit Care Med* 2004; 32: 1781-4.
- 4 Australian and New Zealand Intensive Care Society. Statement on withholding and withdrawing treatment. Melbourne: ANZICS, 2004.
- 5 NSW Health. Guidelines for end-of-life care and decision-making. Sydney: NSW Health, 2005.
- 6 Sprung C, Cohen S, Sjøkvist P, et al; Ethicus Study Group. End-of-life practices in European intensive care units: the Ethicus Study. *JAMA* 2003; 290: 790-7.
- 7 Esteban A, Gordo F, Solsona J, et al. Withdrawing and withholding life support in the intensive care unit. A Spanish prospective multi-centre observational study. *Intensive Care Med* 2001; 27: 1744-9.
- 8 Collins N, Phelan D, Marsh B, Sprung C. End-of-life care in the intensive care unit: the Irish Ethicus data. *Crit Care Resusc* 2006; 8: 315-20.
- 9 Cook D, Rocker G, Marshall J, et al. Withdrawal of mechanical ventilation in anticipation of death in the intensive care unit. *N Engl J Med* 2003; 349: 1123-32.
- 10 Heyland D, Frank C, Groll D, et al. Understanding cardiopulmonary resuscitation decision making; perspectives of seriously ill hospitalized patients and family members. *Chest* 2006; 130: 419-28.
- 11 Faunce T, Stewart C. The Messiha and Schiavo cases: third-party ethical and legal interventions in futile care disputes. *Med J Aust* 2005; 183: 261-3.
- 12 Curtis J, Cook D, Wall R, et al. Intensive care unit quality improvement: A "how-to" guide for the interdisciplinary team. *Crit Care Med* 2006; 34: 211-8. □