

End-of-life care in the intensive care unit: the Irish Ethicus data

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Despite medical advances, the process of dying challenges medical staff daily in intensive care departments. It is accepted that cardiopulmonary resuscitation is not appropriate for all patients,¹ and there is an international trend to withhold or withdraw life-sustaining therapy in dying patients in intensive care departments.² While there is great global variation in the practice of limiting life-sustaining therapy,³ the recent Ethicus Study documents the withholding or withdrawal of this therapy in 73% of all ICU deaths in Europe.⁴

We report the Irish subset of the Ethicus Study, which is the first prospective analysis of deaths in an Irish intensive care unit. Until this study, the frequency of withholding and withdrawing therapy in Irish intensive care was not known. The study examines the associated end-of-life (EOL) decision-making process. It includes patient characteristics, the staff and family who were involved, when decisions were made, and the rationale behind these choices.

This information is expected to inform debate about current clinical and ethical practice in Irish ICUs, and to encourage community reflection on current policy, continuing professional development and patient care.

Methods

The Department of Intensive Care Medicine, Mater Misericordiae University Hospital, Dublin, Ireland, agreed to participate in the pan-European Ethicus Study.⁴ This was a prospective observational study of all consecutive patients admitted to ICU who died or had life-sustaining therapy limited. Its aim was to evaluate EOL practices in ICUs of several European countries, to determine the overall incidence, to document variation and to analyse similarities in the EOL decision-making process.

Ethicus data from all patients who died or had limitation of therapy in the Mater Hospital ICU between 1 September 1999 and 30 June 2000 were collected on a paper study pro-forma by one of five senior medical staff members and checked by the site investigator (country coordinator) before electronic transmission to a central database. Countries and centres were coded for anonymity, and patients were numbered consecutively to ensure confidentiality. Data were transmitted throughout the study by Internet and email to a central processing centre in Israel.⁵ There was a strict validation procedure. Reliability and internal consistency of data were maintained

ABSTRACT

Objective: To study the frequency, rationale and process for withholding (WH) and withdrawing (WD) life-sustaining therapies in intensive care patients in Ireland.

Design: Prospective, observational study, comprising a subset of the European Ethicus Study.

Setting and participants: 122 patients who died or who had life-sustaining therapies limited in the ICU of a university hospital, 1 September 1999 to 30 June 2000.

Outcome measures and results: An end-of-life (EOL) treatment decision was made for 85/122 patients (69%). Forty-five (36%) had therapy withheld, 40 (33%) had it withdrawn, 26 (21%) had unsuccessful cardiopulmonary resuscitation, and 11 (10%) suffered brain death. The median time from ICU admission to death was 4.0 days for WH patients and 2.9 days for WD patients (range, 10 minutes to 123 days). The discussion to limit therapy was initiated by the ICU doctor in 50 cases (59%), and involved families in 66 cases (78%). Families initiated 9% of EOL discussions. Nursing staff were involved in 98% of decisions. No patients were mentally competent, but their wishes were known in 28% of cases. The primary reason for limiting life-sustaining therapy was that the patient was unresponsive to maximum therapy (68% of patients). An EOL decision was made every 55 hours during "office hours" and every 120 hours during "on-call" working hours. Withholding was more frequent than withdrawing during "on call" periods.

Discussion: The frequency of withdrawal or withholding of therapy in this Irish ICU is in line with current international practice. The time to EOL decision-making is variable and relatively short compared with that in the United States, but similar to that in Europe. Clinicians are the primary initiators of the EOL decision in Ireland, with little patient involvement. Family members are more likely to initiate an EOL decision than in Europe. EOL decisions were usually made during "routine" working hours after significant consultation with all groups.

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though the use of hypothetical test case scenarios and discussion at investigator meetings before the study began. Transmitted data underwent real-time audit. There were site visits and retrospective appraisal of selected charts by study investigators.

Table 1. Median time in days* (range) between ICU admission, end-of-life (EOL) decision and death for each EOL category

| | Brain death (n = 11) | CPR (n = 26) | LST withheld (n = 45) | LST withdrawn (n = 40) |
|-------------------------------------|----------------------|------------------|-----------------------|------------------------|
| Hospital admission to ICU admission | 0.1 (0–19.9) | 0.25 (0–174.9) | 2.95 (0–131.7) | 3.03 (0.01–41.2) |
| ICU admission to EOL decision | na | na | 2.93 (0–40.1) | 2.94 (0.08–123.5) |
| EOL decision to death | na | na | 0.4 (0.01–16.1) | 0.4 (0.02–4.36) |
| ICU admission to death | 1.44 (0.35–12.6) | 1.47 (0.01–29.3) | 4.0 (0.01–40.8) | 2.87 (0.1–123.8) |

* All time was measured in minutes but expressed in days. CPR = cardiopulmonary resuscitation. LST = life-sustaining therapy. na = not applicable.

The study was approved by the hospital's ethics committee. The committee waived the requirement for informed consent as no interventions or treatments were given to the patients as part of this observational study, and the process of the study was deemed not likely to affect treatment. A hospital "EOL statement" accompanied each data transmission, stating the hospital's ethos, most particularly that shortening the dying process did not occur. There were no important organisational changes that might have affected EOL decision-making during the period of the study.

EOL categories were prospectively defined using a hierarchical system to identify the most active limitation of therapy for each patient.⁴ Categories were mutually exclusive and comprised:

- cardiopulmonary resuscitation (CPR) — death despite cardiac massage and ventilation;
- brain stem death (BSD) — documented cessation of cerebral function;
- withholding treatment (WH) — a decision was made either not to start or not to increase a life-sustaining intervention;
- withdrawing treatment (WD) — a decision was made to stop or to decrease a life-sustaining intervention presently being given; and
- shortening the dying process (SDP) — a specific act performed with the intention of shortening the dying process, such as intentional overdose of narcotics, anaesthetics or potassium chloride.

The data collected included patient characteristics (age, sex, religion), clinical characteristics, institutional characteristics, who initiated and participated in the treatment decisions, when they were made, and the clinical factors involved. Details of which specific therapies were limited are discussed elsewhere.⁶

Results

Patient characteristics

There were 1146 admissions to the Mater Hospital ICU between 1 September 1999 and 30 June 2000, and 126 patients died during this period (overall ICU mortality rate,

11%). No patient survived after limitation of life-sustaining therapy.

Complete data were obtained for 122 of the 126 patients, and study enrolment and subsequent analysis were confined to this group. The mean patient age was 63.9 years (median, 68; range, 19–86 years); 71 of 122 patients (58%) were male.

End-of-life decision categories

Eighty-five of the 122 patients (69%) had life-sustaining therapy limited: WH in 45 (36%) and WD in 40 (33%). Death was associated with unsuccessful CPR in 26 patients (21%), and 11 patients (10%) died because of brain death. There were no cases of SDP in this study.

The timing of events before death

The time between hospital admission, ICU admission, EOL decision and death is shown in Table 1.

Limitation of intensive life-sustaining therapy: who was involved?

Eighty-five patients had a decision made to limit (WH/WD) life-sustaining therapy. This decision was initiated by the ICU doctor for 50 patients (59%), a non-ICU doctor for 26 (31%), the family for eight (9%) and nursing staff for one (1%). Nurses were involved in the EOL decision for 83 patients (98%), and family was involved for 66 (78%). Nineteen (22%) families were not consulted; six of these were not involved as they were unavailable, and 13 were not asked to become involved as the patients were considered "unresponsive to maximum medical therapy".

Consultation occurred among several types of groups, including the ICU doctor and ICU nurses, the ICU doctor and other doctors, clinical staff and the patient, and clinical staff and the family. There was considerable agreement within groups. Sixty-four patients (75%) had three groups involved in the final treatment decision, 16 (19%) had two groups involved, and five (6%) had one group involved.

No patient had direct input into the EOL decision-making process as none were mentally competent at the time of the discussion. Patients' wishes were known in 24 cases (28%)

Table 2. Reasons for limiting (withholding or withdrawing) intensive life-sustaining therapy

| Reason | Primary reason (n = 85) | Contributory reason* (n = 85) |
|---------------------------------|----------------------------|----------------------------------|
| Unresponsive to maximum therapy | 57 (68%) | 67 (80%) |
| Neurological disease | 14 (16%) | 25 (30%) |
| Multisystem organ failure | 7 (8%) | 45 (54%) |
| Chronic disease | 5 (6%) | 25 (30%) |
| Patient or family request | 1 (1%) | 12 (14%) |
| Poor quality of life | 1 (1%) | 9 (11%) |
| Sepsis | 0 | 38 (45%) |

* As patients often had several contributory reasons, percentages do not sum to 100%.

through family or next of kin. One patient had an advance directive (living will) which contributed to the EOL decision-making process.

Reasons for withholding or withdrawing intensive life-sustaining therapy

Of the 85 patients who had intensive life-sustaining therapy withheld or withdrawn, 66 had more than one reason to limit the therapy. Table 2 details the clinical reasons underlying the WH or WD decisions and categorises them as primary or contributory reasons.

Timing of end-of-life decisions

Forty-six (54%) decisions to withhold or withdraw therapy were made during routine working hours (07:30–19:00 Monday to Friday), 31 (36%) were made over the weekend (19:00 Friday to 07:30 Monday) and eight (9%) were made during weeknights (19:00–07:30 Monday to Thursday). Figure 1 shows the difference in WH and WD decisions between normal working hours and “on-call” (weeknight and weekend) hours.

Withdrawal of therapy was more likely to occur during routine working hours (with 63% of WD decisions made then), while withholding therapy was more likely to occur during on-call hours (53% of these decisions). During routine hours, an EOL decision was made every 55 hours, while during on-call hours an EOL decision was made every 120 hours.

Documentation of end-of-life decision-making

Twenty-six of the 85 patients (31%) had “No CPR” documented, and all these patients also had “withhold or withdraw” written in their charts. A further 35 patients (41%) had “withhold or withdraw” documented but no reference to withholding CPR. Twenty-four patients (28%)

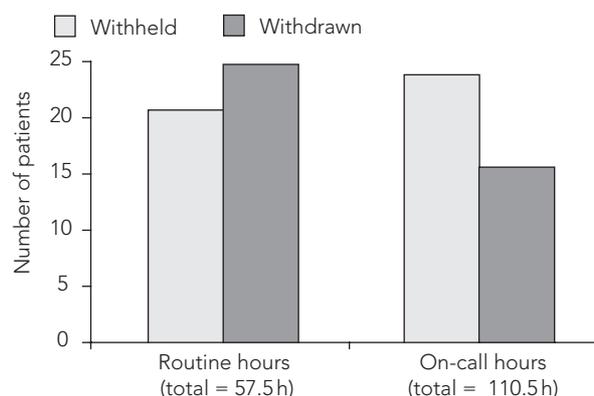
had no documentation in the medical notes stating either “No CPR” or “withhold or withdraw”. Eleven of these 24 patients died within 2 hours of the treatment decision.

Discussion

The incidence of withholding or withdrawal of life-sustaining therapy at the end of life is increasing.⁷ Early studies in the United States⁸ and Australia⁹ showed the incidence to be about 50% of ICU deaths. The figure is now reported as 70%^{4–9} of ICU deaths, although there is variability between cultural groups,³ and a recent Hong Kong report gave an incidence of 58%.⁷ The incidence of WH/WD in our hospital (69%) was comparable with the European mean value,⁴ and with reported US practice.¹⁰

The incidence of unsuccessful CPR (20%) and of brain death (10%) in Ireland were similar to the European mean values.⁴ However, there was a difference in that SDP was reported in Europe (2%) but not in Irish practice. This may reflect a Roman Catholic code of ethics in the Irish participating hospital and also the prohibition against intentional ending of life in both the Code of Ethics of the Irish Medical Council¹¹ and Irish law. No difference was found in the incidence of withholding (36%) and withdrawing (33%) life-sustaining therapy between Irish practice and the European mean.

The Irish data suggest that the decision-making process is faster than that reported in the US¹² and Canada.¹³ The time from ICU admission to death (4.0 days for withholding and 2.9 days for withdrawing treatment) suggests little delay in decision-making. Although inclusion criteria were

Figure 1. Number of patients who had life-sustaining therapy withdrawn or withheld, by time of week*

* Routine hours = 07:30–19:00 Monday to Friday.
On-call hours = 19:00–07:30 Monday to Thursday, and 19:00 Friday to 07:30 Monday.

different, Cook et al¹² demonstrated that the time from ICU admission to death in patients undergoing withdrawal of ventilation was 6 days. Dowdy et al,¹³ in a study of pre-emptive ethics consultation in WH/WD patients, demonstrated that the time to death in the intervention group (14.9 days), even though significantly shorter than in the control group, was still substantially longer than the time to death in our study. The mean time from EOL decision to death in our institution was 9.6 hours, which is comparable but marginally shorter than the 11.3–15.3 hours quoted in the Ethicus Study.¹⁴ This suggests that, although the incidence of WH/WD is similar in European and US ICUs, the process and time course is shorter in Europe.

The shorter intervals observed in our study suggest that the appropriateness of intensive care admission and intensive life-sustaining therapies is under active consideration from the outset. The variation in time intervals (10 minutes to 123 days) suggests that decisions were made on an individual basis and not dictated by length of stay. This shorter time course may represent appropriate clinical practice, as a second report¹⁵ based on the WH/WD patients studied by Cook et al,¹² analysed the level of “clinician discomfort” caused by EOL decision-making. Discomfort was registered by at least one clinician at some stage of the process for 48% of patients, but the discomfort was more likely (by a factor of six) to be caused by undue prolongation of death than by undue haste in limiting treatment.

The decision to withhold or withdraw treatment was mostly (90% of patients) made by clinicians. All patients in the Irish study lacked capacity at the time of the EOL decision. Respect for patient autonomy in terms of not wishing to undergo life-sustaining therapy may have been a factor in 28% of cases in which patients’ wishes were known through next of kin. In one case, the patient’s advance directive determined the decision (a young man with a chronic illness who had vasopressors and antibiotics withdrawn). Cohen et al¹⁶ states in the Ethicus Study that 5% of patients were mentally competent at the time, and 20% of patients had their wishes known through next of kin. There is variation across Europe: in Northern Europe, 31% of patients had their wishes known, and there was discussion with 88% of families, while in Southern Europe 13% of patients had their wishes known, and there was discussion with only 48% of families. The low level of knowledge of patients’ EOL wishes among relatives (about 30%) supports the strong case put by Cohen¹⁶ for encouraging people with serious chronic illness to express their EOL wishes to their next of kin.

In eight cases (9%), the discussion to limit life-sustaining therapy was initiated by the family on the patient’s behalf, a significantly higher percentage than the Ethicus mean¹⁵ (2.1% in Central Europe, 4.2% in Northern Europe and

7.4% in Southern Europe). Generally, Irish data have been closely comparable with Northern European practice, and the similarity in this instance with Southern Europe is atypical. It may be explained by religious similarities, large families and shared cultural attitudes towards dying and death. The Irish Constitution also emphasises the role of the family within society.

In most instances (59%), the EOL discussion was initiated by the intensive care physician, who was twice as likely as other physicians (31%) to initiate the discussion. In Europe, intensivist-initiated discussion was more common at 79%.¹⁴ The primary reason for withholding or withdrawing life-sustaining therapy was because the patient was “unresponsive to maximum medical therapy” (68% of patients), and this reason was four times more common than the next most common — neurological disease. As intensive care physicians are typically in the best position to recognise the futility of “maximum medical therapy”, it is not surprising that they were the primary initiators of EOL discussions — perhaps more especially in ICUs with a “closed” rather than “open” style of practice.

Nurses initiated EOL discussion in Ireland for 1% of patients, and Benbenishty et al¹⁷ demonstrated a comparable figure of 2.1% in the Ethicus Study. However, as data were collected by medical staff, the role of nursing staff may have been underestimated. The involvement of nurses in decision-making was high (98% in Ireland and 78.3% in Europe¹⁶), demonstrating the ongoing importance of critical care nursing professionals in EOL consensus, decision-making and care.

Overall, 19 families (almost a quarter) were not involved in the decision to limit life-sustaining therapy, which may be considered inappropriately high. However, Azoulay et al¹⁸ showed that, in France, 85% of family members did not take part in EOL decision-making, and only 47% of the patient population studied wished to share decision-making. Although Heyland et al¹⁹ documented that good communication with patient representatives is a key quality indicator in terms of family perceptions about the death of a relative in the ICU, it appears that the wishes of individual populations need to be analysed before a desirable standard can be set.

Patient unresponsiveness to maximum medical therapy was the reason given for not consulting the family for 13 (15%) patients, suggesting that obvious acute physiological futility sometimes rendered consultation redundant. Although the overall rate of consultation with the family was perhaps reasonable (78%), it may be argued that family should be consulted for all unresponsive patients, and failure to do so may reflect paternalism. The wide European variation shown by Cohen et al¹⁶ may support this as in Southern Europe, which is traditionally more conservative, only 48% of

families were consulted. The Ethics Committee of the Society of Critical Care Medicine recommends that the primary needs of families include information, the need to understand what is being done to the patient, and assurance that their decisions were correct.²⁰ However, compared with clinicians, relatives are in a less informed position to judge medical futility and may need guidance to avoid feeling that they have "turned off" a loved one.²¹

In this study, there was significant multi-party involvement and consensus regarding the futility of life-sustaining therapy and the advisability of withholding or withdrawing this therapy. Three quarters of patients had three or more parties involved. The number of single-party decisions was low (6%) and compares with the 12% incidence of the Ferrand et al study.²² Girbes²³ counsels for consensus and the avoidance of single-physician decision-making in the ICU setting.

One EOL decision was made every 55 hours during routine working hours compared with one EOL decision every 120 hours during on-call hours. Withdrawing therapy was more common during routine hours, while withholding was more common during on-call time. Possible explanations include the absence at night of family members and the other medical teams required for building consensus or the attendance of on-call teams who may be less familiar with the patient. Withholding treatment is likely to have been preferred by less senior (non-consultant) medical staff who, despite the conventional ethical view that there is no distinction between active (withdrawing) and passive (withholding) actions, are likely to have differentiated between them. This supports the argument that there is a practical difference between withdrawing and withholding life-sustaining treatment.²⁴

Increased debate in the community and at medical undergraduate and postgraduate level would be beneficial. Dealing with death is difficult. Doctors need education and training in this area to empower them to treat patients "with everything that should be done and not everything that can be done".⁸

Conclusion

Life-sustaining treatment is limited in over two thirds of ICU deaths in Ireland. The decision to withhold or withdraw life-sustaining treatment is an individualised one that appears under active consideration from the time of ICU admission. The times between ICU admission and EOL decision and between EOL decision and death in Ireland are comparable with the times in Europe, but shorter than in the US.

The most common reason for limiting life-sustaining treatment is unresponsiveness to maximum medical therapy, and intensivists are the main initiators of EOL decision-

making. Nursing staff make a virtually universal contribution. There is very little direct patient input into the process, and relatives are the main source of information but have specific knowledge of the patient's wishes in only 28% of instances. Good practice recommends consensus EOL decisions, and only a small proportion of patients had only one group involved. This study demonstrated for the first time a difference in decision-making practice between routine working hours and on-call time. This should be studied further to verify its broad applicability and to investigate the underlying reasons.

Future challenges for EOL care include the need for greater education and awareness within the community and medical profession. This study provides a degree of assurance that quality EOL care is inherent to intensive care, but further community awareness and study might provide greater assurance that the pattern of care accords with patients' known wishes.

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