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Analysis of terminal events in 109 successive deaths in a Belgian intensive care unit

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Abstract *Objective:* To determine the incidence of end-of-life decisions in intensive care unit (ICU) patients. *Design and setting:* Prospective data collection and questionnaire in a 31-bed medicosurgical ICU in a university hospital. *Patients and participants:* All 109 ICU patients who died during a 3-month period (April–June 2001). Members of the ICU team were also invited to complete a questionnaire regarding the circumstances of each patient's death. Cardiopulmonary resuscitation was performed in 21 of the patients; other mechanisms leading to death were brain death ($n=19$), refractory shock ($n=17$), and refractory hypoxemia ($n=2$). The decision was taken in the remaining 50 patients to withdraw ($n=43$) or withhold ($n=7$) therapy. Questionnaires were completed for 68 patients, by physician and nurse in

40 cases, physician only in 20 cases, and nurse only in 8 cases. Questionnaires were obtained for 34 of 50 patients for whom a decision was made to limit therapy. *Results:* Respondents generally felt that the decision was timely ($n=28$, 82%), 5 (15%) felt the decision was too late, and one (3%) that the decision was made too soon, before the family could be informed. *Conclusions:* Therapeutic limitations are frequent in patients dying in the ICU, with withdrawing more common than withholding life support. Generally members of the ICU staff were satisfied with the end-of-life decisions made.

Keywords End-of-life decision · Withholding · Withdrawal · Ethics · Intensive care unit · Critical care

Introduction

The time of death in intensive care unit (ICU) patients is often determined by a decision to withhold or withdraw life support therapy [1, 2, 3, 4, 5, 6, 7, 8]. However, the exact frequency of such practices varies from 40% to 90% according to country and cultural differences [8, 9, 10, 11]. In Europe, withdrawing is less common in the southern countries of Greece, Italy, and Portugal than in northern European countries such as Switzerland, Belgium, the United Kingdom, and The Netherlands [8, 9]. In Israel the limitation of therapy in the ICU is rare and when performed is limited to withholding, withdrawal being forbidden under religious law [11]. Critical care physicians

regularly face withholding/withdrawal decisions. In a European ethical questionnaire 96% of physicians said they sometimes withheld treatment, and 77% said they sometimes withdraw therapy [9]. Involvement of the ICU team, with adequate information for the family, can help improve the process of withholding/withdrawing life support [12, 13].

We were interested in determining the exact frequency of such practices in our ICU. We also sought to assess the interactions between the staff, family, and patients during the dying process with a view to improving the care of the critically ill and their family.

Patients and methods

This study was approved by the ethics committee of Erasme Hospital. We prospectively collected data from all patients who died in a 3-month period, between 1 April 1 and 30 June 2001, in a 31-bed, mixed medicosurgical Department of Intensive Care. The Department also includes a shock laboratory for emergency admissions. Data collection included: age, gender, admitting diagnosis, significant comorbid conditions such as cancer, cirrhosis, immunosuppression, and advanced respiratory, neurological, and cardiovascular disease.

We invited the members of the ICU staff to complete an anonymous questionnaire, indicating the mode of death (brain death, cardiopulmonary resuscitation, withholding, withdrawal or death despite full treatment), whether information was given to the family, and whether the family was present at the time of death. If a decision on withholding/withdrawal was taken, we asked that they complete the type of life support modalities withdrawn, use of sedatives, provide an evaluation of the timing of the decision (too late, timely, too quick), state whether they agreed with the decision, and indicate their participation in the withdrawal/withholding act. In addition, we asked that they indicate their feeling towards the decision on a scale ranging between 0 and 10 points (0, totally frustrated; 10 entirely satisfied). The questionnaires were attached to the death certificates so members of the ICU team present at the time of death could complete them.

Results

Over the 3-month period 610 patients were admitted to the ICU, 109 of whom (17.8%) died; their admission diagnoses are listed in Table 1. Only 21 (19%) patients underwent cardiopulmonary resuscitation (CPR). The most frequent diagnosis in these patients was cardiac failure (Table 1). CPR was performed at the time of admission, or was the reason for admission, in 7 patients. Brain death was the cause of death in 19 (17%) patients, two patients died of refractory hypoxemia and 17 (16%) died of refractory shock, including septic ($n=10$), hemorrhagic ($n=5$), and cardiogenic ($n=2$) (without CPR attempts). A decision to forego life support treatment was made in 50 (46%) patients: withdrawal in 43 patients and withholding in 7 (4 intubations and 3 surgical procedures; Fig. 1). The means of withdrawal of life support were: 41 increased sedation, 20 withdrawal of vasopressors, 17 decreased ventilator conditions (FIO_2 , tidal volume), and 4 disconnection from respirator.

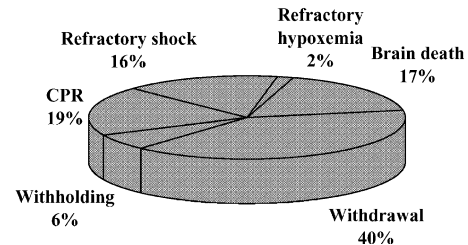


Fig. 1 Terminal events

Questionnaires were completed for 68 of 109 (62%) patients, in 40 cases both by physician and nurse, in 20 by a physician only, and in 8 by a nurse only. Questionnaires were completed for 34 of 50 patients in whom a decision to withhold or withdraw life support was made (in 19 patients by both physician and nurse, in 10 by a physician only, and in 5 by a nurse only).

Patients for whom therapy was withdrawn/withheld were older than those who died without such a decision (65 ± 19 and 58 ± 20 years, respectively, $p=0.05$), but the differences in length of ICU stay were not statistically significant (3.0 ± 9 days vs. 4.4 ± 3 days, $p=0.33$). Deaths in these patients occurred more commonly (67%) between noon and midnight, which may reflect decisions taken on the morning rounds. Relatives were present at the time of death in 38 of the 68 (56%) cases for which questionnaires were completed. Families were said by the respondents to be fully informed about the terminal state in 62 of the 68 (91%). On the satisfaction scale, the mean score was 7.6 for nurses and 7.5 for physicians. In only two cases did the difference between physician and nurse exceed more than 2 points, with the nurse giving scores of 6 and 5 points, respectively, less than the physician. In the first case the nurse felt that the dying patient had been very uncomfortable and dyspneic. In the second the reason for the dissatisfaction was not explained. According to the staff questionnaires, the decision to withhold/withdraw was timely in 28 patients, too late in 5, and too soon in one patient, where the relatives did not have time to reach the hospital before the patient's death (Fig. 2).

Table 1 Admission diagnoses of patients who died in the ICU

	Without limitation of therapy ($n=59$)/unsuccessful CPR ($n=21$)	With withholding, withdrawal decision ($n=50$)
Cardiac failure	8/12	9
Post-CPR	7/11	6
Septic shock	2/10	10
Neurological (medical)	0/9	15
Head trauma	0/7	3
Hemorrhagic shock	3/5	2
Sudden respiratory failure	1/3	5
Polytrauma	0/2	0

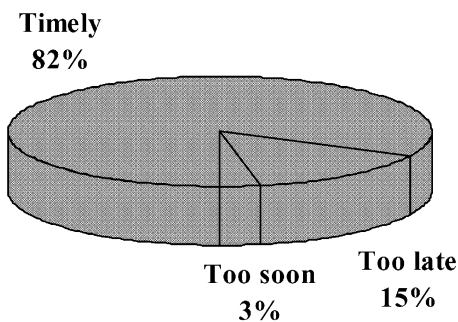


Fig. 2 Staff assessment of timing of decision

Discussion

The present study describes the terminal events in a large population of patients who died in a Department of Intensive Care, almost one-half of whom died after a decision to limit treatment. The majority (86% of patients with limited therapy) died after withdrawal, rather than withholding, of life support. Although ethicists generally agree that there is no difference between withholding and withdrawing life support [10], withdrawal may be more difficult to accept by the caregivers [10], and for some only withholding is permitted for cultural and/or religious reasons [11]. The disproportion seen between withdrawing and withholding decisions may reflect a tendency to give patients the benefit of an "ICU trial," to evaluate the response to maximal initial treatment and then withdraw if no positive reaction is noted, rather than to withhold all treatment from the outset. This strategy has also been reported in other studies but to a lesser extent. In a French survey, 69% of end-of-life decisions were to withdraw, and 31% to withhold [3]. In the United States Prendergast and Luce [2] reported that 78% of end-of-life decisions were to withdraw and 12% to withhold. In the recent European Ethicus study [8] withholding was noted in 37.5% of patients and withdrawing in 32.9%, although there were considerable regional variations.

With current ICU technology able to delay death, the intensivist is confronted daily with questions about reasonable chance of survival, quality of life, and limiting suffering. We undertook a somewhat similar study to the present in our ICU about 14 years ago [14]. The number of patients undergoing a withholding/withdrawal decision has increased considerably (9% in 1989 vs. 46% in 2001). Others have observed similar changes. Prendergast and Luce [2] reported a rise in the number of patients undergoing a withholding/withdrawal decision from 51% in 1987–1988 to 90% in 1992–1993. Another study in two Canadian centers [1] found an increase from 40% to 66–80% between 1988 and 1993. The number of patients undergoing CPR before death has also decreased. In our ICU death followed unsuccessful CPR in 35% of patients in 1989 vs. 19% in 2001. Also in the United States the

number of patients who underwent CPR decreased from 50% in 1987 to 11% in 1993 [2].

There are considerable differences between Europe and the United States in the numbers of deaths preceded by an end-of-life decision. The proportion of patients who died following a decision to limit futile therapy in our ICU (46%) was closer to that in a French [3] study (51%) than to United States [2] and Canadian [7] studies (90% and 80%, respectively). Even with the increasing importance of patient autonomy (particularly in the United States), the ethical principle of beneficence (non-maleficence) is still predominant in most European countries [11]. In Europe there is a general tendency to inform families about prognosis and end-of-life decision, although without their active participation in the decision [11]. In our study the family was reported to have been fully informed in 91% of cases, while in a Canadian study the family actively participated in 94% of end-of-life decisions [7]. Increasingly the family wants to be involved in such decisions [15], and the importance of family involvement is stressed in guidelines regarding end-of-life decision making from various European groups [16, 17]. However, in the recent French LATAREA study 11% of withdraw/withhold decisions were still made with no family or patient involvement [3]. In a Spanish study the family was not involved in 28.3% of cases [18]. Considerable variability thus exists between countries and institutions, reflecting the influence of personal, ethical, social, religious values, and the heterogeneity of available guidelines [10].

There are acknowledged difficulties in classifying events surrounding death, and hence in defining the limits between withdrawing and withholding. For example, in most studies, patients who are declared "brain dead" are considered as a separate group [8, 19], while in others such patients are considered as part of the limited therapy group [2, 11]. We chose *not* to include such patients (17% were brain dead) in our analysis of withholding/withdrawing. Another difficult point to define is the limit between full life support and withholding or withdrawal in some shock states. Giving full support yet no CPR to patients with refractory shock may be seen as withholding. Similarly, not increasing the norepinephrine dose above a maximum of 40 $\mu\text{g}/\text{min}$ may be seen as withholding by some, and yet giving much higher doses would be interpreted as futile therapy. Where should the cutoff be, and who is going to define it? Likewise, not placing cardiac support devices or performing emergency transplantation may be seen as therapeutic limitation. Individual physicians, units, or nations somewhat artificially determine the limits between these categories.

The ICU team reaction to the decision was generally positive, with few disagreements between different members of the ICU team, although there were two cases in which the nurses were less satisfied than the physician. Ferrand et al. [15] recently reported that 73% of physicians but only 33% of nurses felt the end-of-life decision-

making process was satisfactory. Others have also reported differences in attitudes towards end-of-life decisions among various groups of the ICU team [16, 17]. One of the reasons for these differences, suggested by Frick et al. [17], is related to the different roles of the various members of the staff, with nurses spending more time with the patients and their families, making them perhaps more aware of levels of pain and discomfort. Differences in satisfaction levels also vary between hospitals, with Keenan et al. [18] noting that 82% of teaching hospital nurses were satisfied with the withdrawal of life support process, compared to 58% of their community hospital colleagues. Items associated with increased nurse satisfaction included involvement in the plan for withdrawal of life support, comfort with patient sedation levels, comfort with discussions with the family, and increasing experience of withdrawal of life support events. The good agreement between physicians and nurses in our study may be related to the strong team approach that our unit has in end-of-life decision making, where, whenever possible, opinions of all members of the ICU team are taken into consideration before any decision is made.

There are several limitations to this study. First, the results reflect the situation at one ICU and cannot necessarily be extrapolated to other units. Second, our evaluation time was limited to 3 months, potentially introducing a bias of personal practices, as the physicians in training change every 3 months in our unit. Third, the physician or the nurse who was present at the time of death, and not necessarily those who participated in the decision process, completed the questionnaires. Fourth, we obtained a limited number of completed questionnaires, but we wanted the process to be entirely voluntary.

In summary, this study has shown that a considerable number of critically ill patients die as a result of an end-of-life decision. There were more decisions to withdraw than to withhold therapy, although withdrawal is frequently perceived as more difficult. Members of staff agreed with the majority of decisions, and patients' families were generally informed about the decision. Nevertheless, there were a few cases in which it was felt by some that the end-of-life care could have been improved. Further studies are necessary to explore the interactions between critically ill patients, their families and the ICU staff in relation to end-of-life decision making.

References

- McLean RF, Tarshis J, Mazer CD, Szalai JP (2000) Death in two Canadian intensive care units: institutional difference and changes over time. *Crit Care Med* 28:100–103
- Prendergast TJ, Luce JM (1997) Increasing incidence of withholding and withdrawal of life support from the critically ill. *Am J Respir Crit Care Med* 155:15–20
- Ferrand E, Robert R, Ingrand P, Lemaire F (2001) Withholding and withdrawal of life support in intensive-care units in France: a prospective survey. French LATAREA Group. *Lancet* 357:9–14
- Turner JS, Michell WL, Morgan CJ, Benatar SR (1996) Limitation of life support: frequency and practice in a London and a Cape Town intensive care unit. *Intensive Care Med* 22:1020–1025
- Koch KA, Rodeffer HD, Wears RL (1994) Changing patterns of terminal care management in an intensive care unit. *Crit Care Med* 22:233–243
- Faber-Langendoen K, Bartels DM (1992) Process of forgoing life-sustaining treatment in a university hospital: an empirical study. *Crit Care Med* 20:570–577
- Hall RI, Rocker GM (2000) End-of-life care in the ICU: treatments provided when life support was or was not withdrawn. *Chest* 118:1424–1430
- Sprung CL, Cohen SL, Sjkovist P, Baras M, Bulow HH, Hovilehto S, Ledoux D, Lippert A, Maia P, Phelan D, Schobersberger W, Wennberg E, Woodcock T (2003) End-of-life practices in European intensive care units: the Ethicus Study. *JAMA* 290:790–797
- Vincent JL (1999) Forgoing life support in Western European intensive care units: the results of an ethical questionnaire. *Crit Care Med* 27:1626–1633
- Vincent JL (2001) Cultural differences in end-of-life care. *Crit Care Med* 29:N52–N55
- Eidelman LA, Jakobson DJ, Pizov R, Geber D, Leibovitz L, Sprung CL (1998) Foregoing life-sustaining treatment in an Israeli ICU. *Intensive Care Med* 24:162–166
- Swigart V, Lidz C, Butterworth V, Arnold R (1996) Letting go: family willingness to forgo life support. *Heart Lung* 25:483–494
- Abbott KH, Sago JG, Breen CM, Abernethy AP, Tulskey JA (2001) Families looking back: one year after discussion of withdrawal or withholding of life-sustaining support. *Crit Care Med* 29:197–201
- Vincent JL, Parquier JN, Preiser JC, Brimiouille S, Kahn RJ (1989) Terminal events in the intensive care unit: review of 258 fatal cases in one year. *Crit Care Med* 17:530–533
- Sjkovist P, Nilstun T, Svantesson M, Berggren L (1999) Withdrawal of life support—who should decide? Differences in attitudes among the general public, nurses and physicians. *Intensive Care Med* 25:949–954
- Ferdinande P, Berre J, Colardyn P, Damas P, de Marre F, Devlieger H, Groenen M, Grosjean P, Installe E, Lamy M, Laurent M, Lauwers P, Lothaire T, Reynaert M, Roelandt L, Slingeneyer de Goeswin M, Vincent JL (2001) La fin de la vie en médecine intensive. *Reanimation* 10:340–341
- Chevrolet JC (2003) Do not resuscitate orders in intensive care units. Ethical aspects and position of the Conseil d'éthique clinique of the university hospitals of Geneva (Switzerland). *Reanimation* 12:78–87
- 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 (2001) Withdrawing and withholding life support in the intensive care unit: a Spanish prospective multi-centre observational study. *Intensive Care Med* 27:1744–1749
- Keenan SP, Kernerman PD, Cook DJ, Martin CM, McCormack D, Sibbald WJ (1997) Effect of noninvasive positive pressure ventilation on mortality in patients admitted with acute respiratory failure: a meta-analysis. *Crit Care Med* 25:1685–1692