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## Challenges in end-of-life care in the ICU

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**Abstract** The jurors identified numerous problems with end of life in the ICU including variability in practice, inadequate predictive models for death, elusive knowledge of patient preferences, poor communication between staff and surrogates, insufficient or absent training of health-care providers, the use of imprecise and insensitive terminology, and incomplete documentation in the medical records. The jury strongly recommends that research be conducted to improve end-of-life care. The jury advocates a “shared” approach to end-of-life decision-making involving the caregiver team and pa-

tient surrogates. Respect for patient autonomy and the intention to honour decisions to decline unwanted treatments should be conveyed to the family. The process is one of negotiation, and the outcome will be determined by the personalities and beliefs of the participants. Ultimately, it is the attending physician’s responsibility, as leader of the health-care team, to decide on the reasonableness of the planned action. In the event of conflict, the ICU team may agree to continue support for a predetermined time. Most conflicts can be resolved. If the conflict persists, however, an ethics consultation may

be helpful. Nurses must be involved in the process. The patient must be assured of a pain-free death. The jury of the Consensus Conference subscribes to the moral and legal principles that prohibit administering treatments specifically designed to hasten death. The patient must be given sufficient analgesia to alleviate pain and distress; if such analgesia hastens death, this “double effect” should not detract from the primary aim to ensure comfort.

**Keywords** End-of-life care · ICU · Terminal illness

## Introduction

Death, previously a private, usually spiritual or religious event involving family and friends, is today by contrast, often public and technological. The severity of illness of hospitalized patients has progressively increased over recent decades, whilst sophisticated technological support has allowed such patients to survive longer. At the same time, it is increasingly accepted that continued aggressive care may not always be beneficial. Death in the ICU therefore now frequently follows limitation of life-supporting therapies. As a result, the mission of intensive care has expanded to encompass the provision of the best possible care to dying patients and their families.

The International Consensus Conference was convened to discuss some of the challenges posed by these social and medical changes. On 24–25 April 2003 in Brussels, Belgium, a jury of ten persons, including an anthropologist and nine intensivists, attended the presentations of 30 experts in the field of end-of-life care, and the subsequent discussions, with the objective of answering the following five specific questions which were posed to them by the organizers and scientific advisors of the consensus conference (the jury was not allowed to modify the questions):

1. Is there a problem with end-of-life care in the ICU?
2. What is the “epidemiology” of death in the ICU?
3. How does one explain the differences between and within countries and cultures regarding end-of-life care?
4. Who decides to limit life-sustaining treatments in the ICU?
5. What is the optimal care for patients dying in the ICU?

The following document is a synthesis of the ten experts’ opinions, the available literature and 2 days of

deliberation by the jury. It should not be considered as the consensus of each supporting scientific society.

## Question 1: Is there a problem with end-of-life care in the ICU?

The answer to this question is: definitely yes! A number of problems and concerns, and their causes can be identified.

### Terminology

- Sensitivity. Some terms are inherently insensitive—e.g. “withdrawal of care” rather than “withdrawal of intensive treatments”; “futility” implying hopelessness rather than perhaps “undesirable” or “not appropriate”; “terminal weaning” rather than “comfort care”.
- Precision. Many words used are imprecise or ambiguous—e.g. “passive euthanasia”, “active euthanasia”, “terminal weaning”.
- Emotionally laden. Some words have strong emotional resonance in common parlance and should perhaps be avoided, or used with great care and awareness of these overtones—e.g. “paternalism”, “autonomy”, “futility”.

### Variability

There is a wide variability in the practice of end-of-life care [1, 2, 3, 4, 5, 6]. The frequency with which decisions are made to forego life-sustaining treatments, the timing of withdrawal of treatment, the treatments withdrawn and the manner of withdrawal may vary considerably, not

only from country to country but also between ICUs in the same country [7]. Although most people agree that there is no ethical difference between withdrawing and withholding life-sustaining therapies, the difference is considered as crucial by several authors in several countries [8, 9], and the psychological impact of each strategy is likely to be different in practice, for many people. The lack of a consensual approach may not necessarily be a problem. The challenge is to avoid over-treatment, which prolongs suffering and postpones the shift from a cure-oriented to a comfort-oriented approach, while at the same time avoiding precipitous decisions to withdraw treatment which could lead to potentially avoidable deaths.

### Prediction

Decisions to withhold or withdraw life-sustaining treatment are often hindered by prognostic uncertainty, since it is usually difficult to identify at an early stage, and without reasonable doubt those patients who will inevitably die. Typically the prognosis only becomes obvious late in the evolution of the acute illness. Unfortunately, the available severity scoring systems do not predict outcome in individual patients with sufficient accuracy to be useful in end-of-life decision making [10].

### Patient preferences

It is often difficult to determine the preferences of individual patients, and patient preferences may change over time with changing circumstances. Fewer than 5% of ICU patients retain decision-making capacity and there is evidence to suggest that patients do not always receive the care they desire or would have wished [11, 12, 13, 14]. Most patients have not completed advance written (instructive) directives, and a majority have not discussed preferences related to end-of-life care in advance [15]. Also knowledge and understanding of a patient's life-support preferences amongst the family, clinicians and nurses is often poor and this may be compounded by misunderstandings related to the cultural, spiritual and religious needs of the patient and the family.

### Discrepancies between recommendations and practice

There are obvious discrepancies between the widely agreed and approved recommendations of scientific societies and legal guidance and daily practice. The explanations for these observations are not entirely clear.

### Who decides?

Who makes the decision on the foregoing of life-sustaining treatments and how are these decisions made, are serious issues. There is considerable variation between countries in the relative roles played by doctors, nurses and families in the decision-making process [1, 2, 3, 4, 5, 6]. Exclusion of team members from this process may lead to dissatisfaction.

### Communication

Compelling evidence indicates that insufficient and inadequate communication between ICU staff and family members is common and can have serious consequences. Families consistently rate communication with the ICU staff as among their most important concerns and often report dissatisfaction with the patient's treatment, the manner in which they were informed about the diagnosis, prognosis and treatment and in general with the quality of communication with the ICU staff [9, 10]. Careful, sensitive and inclusive communication is probably the key to successful end-of-life care discussions and problems arise when the ICU staff are not sufficiently skilled in this aspect of care.

### Training

Although it is now generally accepted that optimal care for dying patients and their families is a crucial aspect of intensive care practice, the training received by critical care clinicians is frequently inadequate. There is currently a paucity of education in palliative care for health-care providers. Major problems such as pain, discomfort, anxiety, sleep disturbance, unsatisfied hunger and thirst and depression are often not adequately addressed [16].

### Documentation and evaluation

Generally end-of-life care is not routinely subjected to regular evaluation or audit, and end-of-life care decisions, including goals, processes, and discussions with the family, are often poorly documented [3]. The available measurement tools for assessing the quality of end-of-life care need to be refined.

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## Question 2: What is the "epidemiology" of death in the ICU?

Studying death and dying in ICUs is fraught with difficulties ranging from non-uniform definitions, unvalidated survey instruments, incomplete administrative data, and

poor documentation in the medical record. Compounding these problems is the qualitative nature of the information gathered. One of the great challenges facing researchers is how best to define the patient population of interest. The solution has ranged from employing definitions used in diagnosis/disease-specific protocols to the more all-inclusive definitions of patients admitted to an ICU. The resulting populations may vary depending not only on regional and national guidelines for the utilization of ICU beds but also local philosophies about end-of-life care. However, what is common to all studies is that they deal with a population that shares the acknowledgement/medical consensus that further aggressive care is unlikely to be beneficial. Indeed, they also share a final common pathway to death.

When trying to measure the process of care, one is faced with a different set of problems. Information can be gathered by a number of techniques (chart extraction, observational, prospective or derived from administrative data), each having particular advantages, limitations and costs. What the data share is that they are qualitative in nature. In addition, they may not accurately reflect clinical practice because of legal, ethical and societal concerns in the case of surveys, or poor documentation in the case of chart reviews. Prospective observational studies are deemed to be more accurate, but as well as being both labour intensive and expensive, they suffer from the difficulty of generalizing data collected from a small sample size to the population as a whole.

Attempts have been made to understand both caregiver and family attitudes and knowledge about end-of-life care. Surveys and qualitative methods (focus groups) have been used extensively. As this data are frequently based on vignettes or questionnaires, they may not be truly representative of the reaction of these individuals in a real-life situation. Family surveys performed post hoc do however provide a true reflection of satisfaction and may be used to influence practice [17]. A major challenge facing researchers is measuring the outcome of care. Clearly the patient's views cannot be ascertained, so one is left with surrogate markers of outcome which essentially can be divided into material and emotional—the former dealing with the process itself and the latter with the impact of the process on the family and health-care team.

Despite the difficulties facing investigators, the number of publications dealing with this topic is significant and expanding (see Table 1). Current data suggest that 20% of all patients dying in the USA, die in an ICU [24], and there is an increasing recognition of the need to change from a curative to a comfort philosophy of care in a certain subset of patients. In a North American study over the 5-year period from 1988 [19] to 1992 [21], the percentage of patients dying following a decision to withhold or withdraw life-sustaining treatments had increased from 51% to 90%.

Studies in a number of European countries [1, 3, 5, 6, 22] have also demonstrated the increasing number of patients in ICUs for whom curative care is unlikely to succeed and therapy is limited. While both the North American and European experiences demonstrate substantial increases in the number of patients in whom death is anticipated and managed, there are substantial (regional or local) differences in the practice of foregoing life-support treatment. For example, in a European survey, the incidence of withdrawal of life-sustaining treatments ranged from 48% in the North to 18% in the South of Europe [25]—a difference for which there are a number of suggested explanations (*vide infra*).

In a large North American study ( $n=74,502$ ), life support was limited in 70% of the 6303 ICU patients who died [4]. Of greater significance was the large variation in practice between units which could not be explained by the types of ICUs or hospitals, nor by the geographic region of the institutions studied. This variation in practice has been substantiated in other North American studies [2, 12], and is not dissimilar from the differences reported in Europe. It is important to emphasize, however, that it is not so much the variation in practice that is important in this context, as the changing and increasing incidence of the practice of limiting life-sustaining care at the end of life.

There are a great deal of data describing the process of withdrawal of life support both from a mechanistic and an effect perspective. In essence these data emphasize that the process must respect the dignity of the patient and ensure the well-being of family and caregivers [1, 3, 13]. How effectively this approach optimizes and humanizes the dying process is probably best measured by the degree of satisfaction of the family [12] and the health-care team.

Surveys of clinicians have illustrated the differences in their attitudes to end-of-life care (when decisions should be made, who should be involved in these decisions, how care should be withdrawn, and, indeed, whether the practice is or is not acceptable). Moreover individual clinicians frequently admit to differences between their practice and their personal philosophy and beliefs regarding this subject [3, 5, 25, 26]. Nevertheless, it is increasingly recognized that decisions to limit aggressive therapy are best made in a consensual/collaborative manner and should be communicated in a timely fashion to the family and other members of the health-care team [27]. Indeed, the limitations of life-sustaining technology should be communicated soon after the patient's admission to the ICU.

What emerges from reviewing the data is that, although in practice the approach to end-of-life care is often inconsistent, there is general agreement as to what ideally should be done. We should accept and recognize these differences and not strive for equal "quantity" but rather strive for exceptional "quality" in end-of-life care.

**Table 1** Main north American and European epidemiological studies on end of life

Year	Reference	Country	Type of study	Number of patients reviewed (died)	Number of ICUs involved	Period of study	Withholding/withdrawing (%)	CPR initiated (%)	Why decision made	Involvement	Major findings
1990	18	France	Prospective	1191	25/17	1984 (two periods) 1987–1988	32				
1990	19	USA	Prospective	198	6	1987–1988	58	49	Poor prognosis	Family involvement 92%	
1996	20	France	Prospective	139	10	1992–1993	60	10	Poor prognosis in 97%		Patient autonomy respected in disagreement
1997	21	USA	Prospective	200	2	1992–1993	90		Poor prognosis in 97%		
1997	22	Canada	Retrospective	417	Units from three hospitals	1993–1994	70.4		Poor prognosis in 97%	Physicians >60%; nurses <20%	
1998	4	USA	Prospective	6303	131	1994–1995	48				Range varied widely from 0 to 83% in practice of limiting therapy
2000	2	Canada	Retrospective	439	Units from two hospitals	1988	43–46/ 66–80				Two periods studied showing increasing incidence
2001	23	France	Prospective	208	26	1 month in 1999	50				In many cases decision did not follow US guidelines
2001	1	Spain	Prospective multicentre	644	6	1996	35			Physicians in 92%; family not involved in a third of patients	
2001	3	France	Prospective	1175	113	1997	53		Poor expected quality of life	Physicians 34%; physicians + nurses 54%	Withholding/ withdrawing practised despite legal prohibition

### **Question 3: How does one explain the differences between and within countries and cultures regarding end-of-life care?**

That there are significant differences between end-of-life care in Europe and North America, and there is no doubt that there are wide variations between and within countries and between individual units, although some of the differences may be more apparent than real and recent evidence suggests that there has been some convergence in practice. To summarize, these differences involve discrepancies in the rates of withdrawing and withholding treatments, the frequency with which ICU admission is refused, and the proportion of ICU deaths preceded by DNR. Other differences include the use of advanced directives, the designation of surrogates, and the involvement of families in end-of-life decision-making. There is also considerable variation in the extent to which nurses and other professionals are involved in these decisions, the type of therapeutic interventions most frequently withdrawn, and the role of ethics consultants or committees.

It is, however, easier to document the differences than to explain them. Although it has been suggested that the attitudes and actions of clinicians, patients and surrogates may be influenced by differences in applicable laws and the organization of intensive care, as well as their religious and cultural background, there is only limited evidence to support these contentions. It is also possible that the attitudes of patients and families may be influenced by age, gender, educational level, income, personal and clinical experience, the patient's functional status, and whether or not they have access to government-financed health care.

#### **Legal framework and national or professional societal guidelines**

Respect for the autonomy of patients is now paramount in medical practice in the United States and is deeply rooted in American culture. Thus, the patient in the United States has an unambiguous right to refuse life-prolonging therapy, and physicians have an obligation to respect this right. As has been mentioned, however, the concept of autonomous choice is usually not directly applicable to intensive care patients since fewer than 5% are able to communicate when treatment decisions are being made. Because US law is determined to support the principle of autonomous choice under all circumstances, advance health-care directives, health-care proxies, or the choice of proxy based on a hierarchical list have all received legal recognition.

Disappointingly, a minority "pro-life" opinion in the USA continues to press for legislative and judicial endorsement of the primacy of the value of life and some

states have responded by limiting the role of surrogate decision makers, even if chosen by a previously competent patient. Several states now specify that health-care proxies cannot decide to withhold nutrition or hydration and in two states, proxies or families must provide clear and compelling evidence that withdrawing life support would be in accordance with the patient's wishes. Since so few patients provide this level of evidence before falling ill, this requirement places additional burdens on surrogates trying to make reasonable choices for their loved ones.

Most European legislations have not specifically addressed the issue of foregoing life support in the terminally ill, although euthanasia is explicitly forbidden (except under certain special circumstances in Belgium and the Netherlands). Even though legal action is still relatively rare, concern is growing that widely accepted medical practices in end-of-life care might not be supported by the courts and a significant proportion of intensive-care clinicians acknowledge that concerns about litigation influence their decisions about treatment limitation. Some doctors have responded to this climate of uncertainty by preferring not to discuss in any detail their intentions and actions with the family and by avoiding what could prove to be potentially incriminating documentation [3, 22], although many would consider the opposite approach to be more expedient.

The legal climate in Europe appears to be evolving, however. The European Commission has ruled that the patient has the right of self determination, including the right to refuse unwanted therapies. Additional guidance comes from the European Convention on Human Rights which requires that a person's right to life be protected by law, prohibits inhumane and degrading treatment, and requires respect for private and family life. Recently, laws pertaining to patient rights have also been proposed in France and Belgium which state explicitly that doctors must respect the refusal of care by competent patients; indeed law suits have been based on doctors' violations of individual freedom.

At the same time, a convergence of opinion about good practice at the end of life appears to be developing among professional societies in the UK and Europe (Table 2) and in the United States. The majority of deaths in the ICU are, or should be, anticipated and thus properly managed. Such deaths should be preceded by decisions to limit or withdraw aggressive treatment and concentrate on the provision of "comfort care", the desirability of achieving consensus with the family, and the need to make the process open and accountable are central to nearly all the current recommendations.

Despite this encouraging degree of agreement, there is an important transatlantic divergence as to who has the final decision if the patient is incompetent. Guidelines from the UK and other professional societies in Europe clearly indicate that this responsibility lies with the doctor

**Table 2** Similarities between the views of European professional societies derived from a questionnaire sent to 19 intensive care societies of 16 European countries, of which 15 societies from 12 countries responded (presented at ICC Brussels April 2003 by Jean-Michel Boles)

Refer to the basic ethical principles of: autonomy, beneficence, non-maleficence, proportionate treatment, and distributive justice. Several state that the need for an ICU bed for another patient should not be a reason for withdrawing treatment.

Recognize the necessity for the limitation of life-prolonging treatments when the clinical situation is hopeless and a treatment appears either futile or inadvisable. Several societies state that there is no ethical difference between withholding and withdrawing life-prolonging treatments. Although many clinicians are reluctant to withdraw treatments once they have been introduced, it is suggested that a treatment may be withdrawn if it has proved to be ineffective.

Underline the importance of the decision-making process which must be based on a thorough evaluation of the situation made by the attending ICU physician over a sufficient time course to ascertain the hopelessness of the situation.

Advocate taking into account the patient's will when he/she is capable of expressing it. The Finnish, British and French societies have defined patient competence. Scotland and France have laws specifying that a surrogate may be designated by the patient.

Recommend keeping the family totally informed and taking its opinion into account. The British ICS, the French SRLF, the Swiss SSICM underline the desirability of consensus amongst the family. All recommend that the burden of the decision should not be put upon the family. Most recommend more or less explicitly the need to provide psychological support to the family.

Stress the need for a general consensus with all the medical staff and the nurses taking care of the patient. Only the German DGAI does not suggest including the nurses in the discussion. In all countries, the final decision is the personal responsibility of the clinician alone.

Strongly recommend that all decisions, and discussions for some, be recorded in the patient's notes.

Recommend that it is the physician's duty to initiate the withdrawing of life-sustaining techniques but indicate that the nurse may be involved depending on the procedure to be withdrawn.

Recommend implementing a thorough palliative care strategy once the decision to withhold or withdraw life-sustaining treatments has been made. Recommendations include analgesic and sedative agents in adequate doses, compassionate care, maximal possible access and privacy. Religious rites must be allowed and respected.

Take a strong position against euthanasia, which is illegal or forbidden by national medical associations in most countries.

in charge of the patient's care. The General Medical Council of the UK states that "It is important to take time to try and reach a consensus about treatment and it may be appropriate to seek a second opinion or other independent review. However, if a patient wished to have a treatment that—in the doctor's view—is not clinically indicated, there is no ethical or legal obligation on the doctor to provide it". The British Medical Association has published the statement: "Whilst the views of those close to the patient are an important factor to take into account in reaching treatment decisions, ...ultimately, the treatment decision is not their right or their responsibility. Rather, the decision will be made by the clinician in charge of the patient's care on the basis of what he or she considers will benefit the patient". Similar views have been expressed recently by the Belgian Society of Critical Care: "In general, the family and relatives should be informed about diagnosis, prognosis and treatments. The information that family may provide is particularly useful when the patient cannot speak for himself about his own end of life. However, the family has no decision-making capability."

By contrast, although the three professional societies in the USA (ATS, SCCM, and ACCP) [28, 30] strongly support the shared decision-making model, none of the three advocate that the primary or ultimate decision should rest with clinicians, and the SCCM recommendations explicitly state that care should be consonant with applicable legal norms (see above).

#### Religious and cultural influences

Most societies are increasingly multicultural and multi-racial, with a diversity of religious beliefs, and deficiencies in end-of-life care tend to be more pronounced in ethnic minority populations [31]. Recognizing this pluralism is therefore fundamental to the provision of high-quality end-of-life care.

There is evidence to suggest that the religious background of the clinician can influence the provision of end-of-life care. Some surveys, for example, have indicated that the proportion of Catholics as opposed to Protestants and agnostics within different countries may explain some of the differences in the incidence of treatment limitations across Europe, with Catholic clinicians being less likely to withhold or withdraw treatment than their Protestant or agnostic counterparts [5]. Further, religious respondents are less likely than nonreligious respondents to feel that they should sometimes withdraw treatment or administer drugs until death ensues [5]. It seems that clinicians from Switzerland, the UK, Belgium and the Netherlands withdraw treatment more commonly than do those from Greece, Italy and Portugal [5]. Deliberate drug administration also appears to be more common in Northern European countries (France, the Netherlands and Belgium) than in Portugal and Italy [5]. Similarly, a US study indicated that Catholic clinicians are more reluctant to withhold life-sustaining treatment [32]. It is however, often difficult to disentangle the influence of religion from that of country of origin in such surveys.

In a survey of neonatal ICU physicians, variations in decision-making were related more to culture-related and other country-specific factors than to the characteristics of individual physicians or units [33]. The frequency with which neonatologists reported withdrawal of mechanical ventilation was highest in the Netherlands, the UK and Sweden, intermediate in France and Germany, and lowest in Spain and Italy. In only the Netherlands and France did substantial proportions of respondents report the administration of drugs in hopeless cases with the purpose of ending the patient's life. Physicians more likely to agree with ideas consistent with preserving life at all costs were from Hungary, Estonia, Lithuania and Italy, while those more likely to agree with statements that quality of life must be taken into account were from the UK, the Netherlands and Sweden [34].

Not only may the religion, ethnicity and culture of clinicians shape their attitudes and approaches to end-of-life care, but these factors also fundamentally influence the hopes and aspirations of patients and their families [35]. Culture determines how individuals make meaning out of illness, suffering, and dying. Because of increased global migration, intercultural interactions between and among patients and health-care professionals of diverse ethnic groups have become a daily event, considerably increasing the risk of cross-cultural misunderstandings. Certainly cultural differences in attitudes toward truth telling, the use life-prolonging technology, and decision-making styles at the end of life can inhibit satisfactory communication. For example, the Muslim cultural edict against informing patients that they have a terminal diagnosis is antithetical to the US concept of patient autonomy and informed consent, yet within the context of the religious and cultural belief of Muslims, to enforce telling the patient directly would be unethical.

Cultures are not, of course, static or homogeneous. Even within a particular ethnic group, there may be significant differences depending on country of residence, gender, age, education, social circumstances, generation and assimilation into the host society. Stereotypes and generalizations are therefore usually wrong. For example, significant differences have been found in end-of-life decision-making styles between Japanese in Japan and Japanese-speaking and English-speaking Japanese Americans in California, although interestingly these differences were greatest between the Japanese speaking Japanese in the USA and the other two groups [36].

The Orthodox Jewish faith is in many senses a special case. According to Jewish law or *Halacha*, human life is of infinite value and beyond measure; any part of that life is therefore of the same worth. Accordingly, physicians are required to do everything in their power to prolong life and hastening the patient's death is equated with murder. The termination of a continuous life-sustaining treatment such as mechanical ventilation is prohibited, although the withholding of such therapies and the ter-

mination of an intermittently administered treatment is allowed [14]. Importantly only the Orthodox Jews rigidly adhere to the *Halacha* and the approach to withdrawing therapy will therefore depend on the precise background of the Jewish patient, family, or clinician.

Thus, what constitutes a good or bad death is largely based on the individual opinions of those involved, which may be strongly influenced by their ethnicity, culture and religion. Recognizing this, the US Institute of Medicine (1997) characterized a "good death" as one that is: free from distress and suffering, consistent with patient, family and caregiver wishes, and largely consistent with ethical, cultural, and clinical standards [37].

#### Differences in the organization of intensive care services

Substantial, largely unexplained variations in the organization of end-of-life practices have been reported. For example, it seems that decisions are more commonly made by clinicians alone in southern European countries and by the intensive care staff as a whole in the UK and Switzerland [5]. Indeed in one Spanish study, nurses were never involved in decisions to withhold or withdraw life support, although they were always informed of the decision [1].

It also seems that organizational factors may influence the approach to end-of-life care. For example, patients dying in a medical ICU under care of staff intensivists were more likely to undergo the active withdrawal of life-sustaining therapies than those with a private attending physician [38], perhaps because, in general, intensive-care specialists have more experience, are more available, provide more appropriate care for dying patients and are more comfortable with treatment limitation. Importantly, in this study the ratio of actual to predicted mortality was lower in those patients cared for by an intensivist than in those managed by a private attending physician.

Cost may have a greater influence on decisions to limit therapeutic efforts in the USA than in some other countries. Patient reimbursement status [39], case mix, and hospital type (University versus Community) [40] may influence the frequency with which life-sustaining treatments are withdrawn, although such factors are probably not the most important influences on decisions to withhold or withdraw care. The influence of the availability of intensive-care facilities on end-of-life care is unclear. In one survey, ICU admissions were frequently limited by lack of beds (particularly in Greece, Italy, Portugal and the UK), and yet three quarters of clinicians still admitted patients with no hope of survival for more than a few weeks [5].

To date, the role of ethics committees and consultants in the daily activities of ICUs has in general been limited to exceptional cases and their overall impact on the day-to-day end-of-life decision-making in the ICU has been

minimal. However, some recent evidence suggests that more routine use of a readily available, responsive ethics consultant may result in a measurable improvement in end-of-life care [41], and ethics committees have been valuable in establishing institutional policies and guidelines.

The differences in the selection and order of treatments to be withdrawn, in particular the more frequent use of withdrawal of mechanical ventilation and extubation in the USA, is difficult to explain, but may be related more to factors such as familiarity, expense, invasiveness and family preferences than to specific legal frameworks or organizational influences [42].

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#### **Question 4: Who decides to limit life-sustaining treatment in the ICU?**

Ethical principles and the decision to limit life-sustaining treatments

The overriding goal for all involved parties should be to act in the patient's best interests. The decision to limit life-sustaining treatments in the ICU should be based on widely held ethical principles such as autonomy (the right of patients to make their own health-care decisions), beneficence (health care should benefit the patient), non-maleficence (health care should do no harm), and distributive justice (resources should be used in a fair and equitable manner). Reasons for withholding or withdrawing therapy may therefore include patient refusal, the unlikelihood that a patient will benefit from a therapy because of a poor prognosis, or the failure of a therapy to improve a patient's condition after a reasonable trial. Application of these principles may, however, be complicated. There may be conflict, such as when the family of a terminally ill patient demands a costly therapy that consumes scarce resources, and not all individuals or societies fully accept these ethical principles, so that decision-making may vary.

The decision to limit treatment must be made with great care and is sometimes agonizing for all participants. As discussed above, the patient's desires and values should guide the process, although these may be difficult to determine when the patient is mentally incapacitated. The concept of "futility" (that is that an intervention will not be beneficial) is often invoked to justify limitation of treatment, but there is no universally accepted standard for futility, and the likelihood of benefit must be deemed to be very low before an intervention can be considered to be futile (some ethicists have suggested <1%). Making this judgment can be very difficult, because standard severity of illness scores are not sufficiently accurate to be applied to individual patients, and even experienced clinicians have difficulty in assessing the prognosis with confidence. Not only the likelihood of survival, but also

the anticipated quality of life if the patient were to survive, should be considered. For example, life-sustaining treatment might be withdrawn from a patient who has suffered a massive stroke if it is perceived that he would consider his quality of life (hemiplegic and aphasic with a permanent tracheostomy) to be unacceptable. On the other hand, other patients might find life supported by permanent mechanical ventilation acceptable as long as their mental faculties are intact.

Decision-makers

#### *The patient or surrogate*

The principle of patient autonomy designates the patient as the ultimate decision-maker. However, it cannot be applied to the majority of patients dying in the ICU, because fewer than 5% have sufficient mental competency to make their own decisions [21]. "Advance directives" such as living wills or durable power of attorney were created to deal with this problem by allowing patients to make decisions in advance. Despite the superficial appeal of this approach, however such directives have not proved to be particularly useful in the management of mentally incompetent ICU patients; they are often ignored by caregivers [43], have been filled out by fewer than 10% of patients admitted to ICUs, and have been shown not to affect patient outcomes, including quality of life or hospital length of stay or use of CPR [44]. On the other hand the durable power of attorney allows the patient to select surrogate decision-makers in advance, and this may be very helpful in minimizing subsequent family conflicts during the decision-making process.

Because most patients have not identified a surrogate prior to ICU admission, some countries have legislated that the closest relative (in the order of spouse, parents, adult children and siblings) can provide "substituted judgment" to serve the patient's interests. If no such relatives exist, unrelated significant others or friends can fulfil this role. In some countries, a court appoints the surrogate. Using a surrogate has limitations, however. Some studies have found that surrogates often fail to accurately represent the patient's wishes [45, 46], and others have shown that family members of dying patients have high rates of anxiety and depression [47], perhaps compromising their decision-making capability. Some clinicians also believe that the family/surrogates should not be burdened with making end-of-life decisions, although anxious and depressed family members have not expressed a desire to be removed from the decision-making process [48], and the possibility that they might feel even more stress if excluded has not been examined.

### *The health-care team*

*Clinicians.* The attending clinician is ultimately responsible for the patient's medical care in the ICU and is clearly in the best position to assess response to therapy and prognosis. In addition, numerous other clinicians may be involved in the care of patients in the ICU, and should also participate in end-of-life decision-making. A primary care clinician who has previously cared for the patient, consultants with expertise in the prognosis of particular diseases and operating surgeons in postoperative patients should also be involved. Doctors in training who participate in the care of dying patients in academic centres should be included in end-of-life discussions, partly because of its importance in training, but should not discuss end-of-life issues with surrogates without being closely supervised. Although clinicians are considered to have the ultimate responsibility for making end-of-life decisions throughout Europe, there may be difficulties when clinicians act as the sole decision-makers; they often fail to accurately predict patient desires regarding end-of-life treatment [45], and may be unaware of patient personal values or religious beliefs that may be important in determining the appropriate aggressiveness of care. Moreover, sole decision-making by doctors does not acknowledge the wishes of the majority of European relatives to be involved in such decisions.

*Nurses.* There is no doubt that nurses should be involved in decisions to limit care. This is often not the case, however, as has been demonstrated in surveys in which nurses have expressed dissatisfaction with their lack of involvement in such decisions [49]. Nurses often have closer and more prolonged contact with patients and their families and may provide valuable insights into patient/family feelings and opinions [50]. Although they should not be expected to make end-of-life decisions, they are important collaborators who can facilitate the process and help patients/families to cope with their inevitable distress.

*Other team members.* Other health-care team members may also be valuable participants in the decision-making process. For example, respiratory therapists or physiotherapists may sometimes have important insights into the status of patients with respiratory failure. Moreover the psychological and spiritual aspects of coping with illness should not be overlooked. Thus, clergy, social workers or psychologists may be crucial in assisting patients/families deal with the stress and depression that often accompany end-of-life decision-making [51].

### The decision-making process

#### *The ideal*

A perceived dichotomy exists between the North American approach to end-of-life decision-making and that in certain European countries, particularly those in the South. The former is seen as favouring patient "autonomy" (or patient/surrogate-directed) and the latter "paternalism" (or physician-directed). More recently, the USA and some European countries have been moving toward the "shared decision" paradigm, a movement that has been stimulated in part by studies showing that patients want their families to act as surrogates in the event that they become mentally incompetent and that many favour joint decision-making with the clinicians. In North America, Canadian polls have shown that 87% favoured the family as decision-maker if the patient became incompetent [52] and 84% supported the right of the family to withdraw life support from a comatose patient [53]. In a French survey, nearly two-thirds of patients interviewed in an emergency ward preferred to have their family make health-care decisions for them [54]. In a poll of lay people in Sweden, 73% preferred that their families and physicians jointly make end-of-life decisions [55].

Thus, there is widespread support among lay people in many countries favouring the involvement of families in health-care decision-making. Also, laws governing patient autonomy long in existence in the US and more recently enacted in Belgium and France recognize the rights of patients to refuse care, even if death may ensue. Consensus bodies from critical care societies in the US as well as most European countries agree that good communication between the caring team and families is essential (Table 2). However, these bodies differ in their view on the extent of family involvement in decisions. In the US, the family (or surrogate) is considered a full participant in the decision, in consultation with the physician, whereas most of the European national societies view the final decision as the physician's sole responsibility.

The jury of the Consensus Conference advocates a "shared" approach to end-of-life decision-making. The jury sees this as a dynamic process with responsibility for the decision being shared between the caregiver team and patient surrogates. The purpose is to reach consensus on a process that is in accordance with the patient's values while providing comfort and support to the family and surrogates. The process should begin early during the ICU admission with a meeting to inform the family about their loved one's illness and of the possible need to limit care if there is lack of improvement or further deterioration. This gives the health-care team an opportunity to gain a better understanding of the patient's background, including his or her culture and religion, and to build a collaborative relationship with the family. Such meetings, when con-

ducted in a standardized, multidisciplinary fashion, have been shown to facilitate transfer to palliative care settings and shorten ICU stays for dying patients [56]. Subsequent meetings are held as needed to update the family on the patient's condition and to discuss end-of-life issues. The meetings should be focused on the patient and family, using non-technical language, with ample time to allow for questions and consideration of the patient's personal values and goals of therapy [57]. Whenever possible, all members of the health-care team should attend these meetings, including nurses, other treating physicians, clergy and consultants as deemed appropriate. Even if one family member has been designated as the surrogate, all interested family members should be encouraged to participate in these meetings, so that a consensus can be reached and family conflicts promptly addressed. Of course, day-to-day updates can be channelled through the one designated surrogate.

The "shared decision" paradigm allows for variations in family/surrogate wishes regarding participation in the decision-making process. A Canadian survey of families showed that 15% wanted the physician alone to decide, 24% wanted the physician to decide after considering their opinion, 39% wanted to share responsibility for the decision, 22% wished to decide after physician input, and 1% wanted to make the decision alone [58]. The process is one of negotiation, with the ICU team providing information on the patient's medical status and prognosis, as well as recommendations and guidance on the best course of management from a medical perspective. The family provides insight into the patient's premorbid health status, beliefs and wishes. The negotiation should be conducted in an atmosphere of mutual respect and trust. The outcome will be determined by the personalities and beliefs of the participants, and, ideally, all should be involved in the decision, culminating in a shared agreement. Documentation of the meeting is also extremely important to provide a record of the proceedings and to serve as a reference should questions arise in the future. The amount of sharing can range from "patient/surrogate-directed" to "physician/health-care team-directed", depending on the family's desire for participation, but ideally, should fall somewhere in between. If the family wants to make the decision, relying on ICU team guidance, the model works well as long as the ICU team concurs with the family/surrogate decision.

Ultimately, it is the attending physician's responsibility, as leader of the health-care team, to decide on the reasonableness of the planned course of action. Conflicts may arise, such as when a family insists on continuation of life-sustaining therapy against the advice of the ICU team. Such conflicts may be common, having been reported in up to 48% of cases [59], although adequate communication, as described below, is likely to greatly reduce the incidence of such disagreements. In the event of conflict, the ICU team may agree to continue support

for a predetermined time, following which the situation will be reassessed with the family. If the conflict persists, however, an ethics consultation may be helpful in bringing resolution. Physicians can suggest that the family seek care under another physician or in another institution, although this is rarely a practical solution. Occasionally, legal advice may be sought. The key to success with the "shared decision" model is communication. Most conflicts can be resolved and unrealistic requests from the family minimized if discussions focus on goals, prognoses and treatment options from an early stage [60] and if the parties understand and trust one another. On average, physicians speak 75% of the time during meetings with the family, but family satisfaction is greater if physicians spend a smaller proportion of the time talking and more listening [57]. The success of the "shared decision" model also depends on the willingness and availability of the ICU team to make time for these discussions: an institutional commitment to supply adequate numbers of physicians, nurses and other personnel, and to assist with their training is therefore a prerequisite. Research is also needed to delineate the optimal approach to the decision-making process in order to best serve patients' interests and maximize satisfaction among families and caregivers.

The "shared decision" model offers advantages over either a family/surrogate-directed approach or a physician/health care team-directed approach. Families may have limited ability to comprehend medical aspects of care and surprisingly little insight into their loved one's wishes [46]. They may have conflicts of interest, such as the belief that they will benefit financially from their loved one's demise, or they may feel excessively burdened by their perceived need to participate in the decision-making process [48]. The "shared decision" process can mitigate these potential difficulties, because the collaborative relationship between the health-care team and family can provide better insight into family dynamics, and help surrogates to better understand the medical issues. Furthermore, the health-care team provides emotional support to the family, sharing the burden of decision-making and helping them to deal with the inevitable distress. At the opposite extreme, the physician/health-care team-directed approach can become overly "paternalistic"; in some cases the process may then be conducted insensitively, without listening to family/surrogate concerns and neglecting the patient's cultural or religious background. Sometimes clinicians react to their own conflicts of interest or feelings of guilt, such as when a surgeon is reluctant to withdraw therapy from a dying patient after a long and complicated operation. By encouraging full participation of families/surrogates in the decision-making process, the likelihood of such pitfalls can be minimized.

### *The reality*

The variable degree to which families are involved in end-of-life discussions is striking and in many institutions around the world families/surrogates are often not involved in their loved one's end-of-life decisions. The LATAREA and PROTOCETIC studies conducted in French ICUs found that families were involved in end-of-life decisions in only 44% and 17% of cases, respectively [3, 22]. As noted elsewhere, a European survey found major differences in the behaviour of clinicians practising in Northern vs Southern Europe [5], with those in the South being less likely to involve the patient's family in decision-making. A discrepancy was also noted between the beliefs of Southern European physicians and their behaviour. Although most agreed that families should be informed about end-of-life decisions, this was actually done in only a minority of cases. Thus, the reality is far from the ideal, particularly in some regions. The jury of the Consensus Conference acknowledges that there is considerable variability between individual physicians, even in the same institution, regarding end-of-life decisions, and that in some instances, religious, cultural or legal issues may be overriding. However, the jury advocate a movement toward the shared decision-making paradigm described above as one that injects more balance into the process and best serves the interests of the patient as well as the underlying ethical principles.

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### **Question 5: What is the optimal care for patients dying in the ICU?**

Optimal care for patients, both living and dying in the ICU involves focusing from the very beginning on comfort as well as cure. Palliative care must begin from the moment the patient enters the unit [61]. The goal is achievement of the best possible quality of life for patients and their families. By way of explanation, palliative care:

1. provides relief from pain and other distressing symptoms
2. intends neither to hasten nor to postpone death
3. affirms life and regards dying as a normal process
4. integrates the psychological and spiritual aspects of patient care
5. offers a support system to help patients live as actively as possible until death
6. offers a support system to help the family cope during the patient's illness and in their bereavement.

For optimal care the ICU personnel must work as a team. Nurses must be involved in team efforts, they should be encouraged to voice concerns about specific patients and procedures and should be heeded when they

do so. It is also important that nurses' rapport with families be appreciated and supported, since the comfort and satisfaction of the family during the painful dying process often depends upon this relationship [62]. Trainee doctors must be encouraged to work with nurses and senior medical staff to offer informed concerned care to patients and families. A multidisciplinary team approach has frequently been found to be effective when dealing with the strong emotions aroused in families and caregivers when a patient is dying and is recommended by a number of professional associations [61, 63].

Comfort care has several essential dimensions: physical, social and spiritual. First and perhaps foremost, the patient must be assured of a pain-free death [61, 64]. The jury of the Consensus Conference subscribes to the moral and legal principles that prohibit administering treatments specifically designed to hasten death. The patient must be given sufficient analgesia to alleviate pain and distress; if such analgesia hastens death, this "double effect" should not detract from the primary aim to ensure comfort [64, 65]. Cure of the patient's body is a crucial goal of intensive care, and the need for physical comfort affects the stay of every patient in the unit. However, for a patient who cannot be cured, the ICU team has little but comfort to offer.

The team must be aware that the provision of comfort should involve the family as well as the patient. For this, trust is essential. Early meetings with the family have been shown to help establish such trust [62]. These meetings communicate compassion and caring more successfully than any slogans or publicity. During the process of withdrawal of intensive treatments, the surrogate or family member's perceptions about the patient's level of pain or distress should be sought and this perception may assist the ICU team's titration of analgesic and sedative dosing for the provision of a good death.

When caring is central to the philosophy of ICU management from the beginning, then good end-of-life care becomes an intrinsic attribute of intensive care. Rather than thinking in terms of "withdrawing" or "withholding" therapies, we can think in terms of "shifting from cure to comfort care".

When we perceive patients as being enmeshed in a web of social and familial relationships, it is then easier to appreciate that death will sever these significant connections. Caring includes attention to the effect of the patient's condition upon the family and loved ones. For optimal care the team must feel responsible for the well-being of the family as well as the patient. The family must be informed and involved in working with the team [23, 66, 67], and must be helped to feel they are not alone. Families who indicate the desire to do so may be involved in the decision-making process, if only to the extent of informing the ICU team what kind of person their loved one was and, if they know it, how their loved one would have preferred to be treated. A recent paper by Cook et al.

[68] shows that this is nowadays a key determinant of withdrawal of mechanical ventilation decisions, far more important than age or severity of illness. However, families are never to be given the sole responsibility, nor must they be given the sole burden, for making what are ultimately clinical and difficult decisions.

Young doctors must be trained to deliver such informed, compassionate care. This must be imparted in medical school and during postgraduate medical training and is taught in part by example, by observing teachers who habitually offer comfort as well as cure. Acquisition of these skills also requires instruction in communication [56, 68, 69, 70]. Doctors, young and old, must learn to speak to patients and families in simple language.

The jury strongly recommends that research be initiated, conducted and founded to improve end-of-life care.

As David Kuhl observed at the International Consensus Conference on Challenges in End-of-Life Care in the ICU, “ours is a death-denying society”, and “ours is a death-denying profession”. One of our greatest challenges is learning to regard dying as a normal process. Doctors must learn to feel at home with the concept of death [71], in order to help patients achieve a death with dignity. To quote Cicely Saunders [73]: “The dying need the friendship of the heart—its qualities of care, acceptance, vulnerability; but they also need the skills of the mind—the most sophisticated treatment that medicine has to offer.” Intensive care physicians have all been given superb training in the skills of the mind. For optimal care they must learn to offer the crucial “friendship of the heart”.

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