Abstract

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 hospitalised 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 might 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 10 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 to answer five specific 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 experts’ opinion, the available literature and 2 days of deliberation by the jury.

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Keywords: End-of-life; Life-sustaining; Life-supporting
1. 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.

1.1. Terminology

1.1.1. 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”, “comfort care” rather than “terminal weaning”.

1.1.2. Precision

Many words used are imprecise or ambiguous—e.g. “passive euthanasia”, “active euthanasia”, “terminal weaning”.

1.1.3. 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”.

1.2. Variability

There is a wide variability in the practice of end-of-life care [1–6]. 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.

1.3. 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].

1.4. Patient preferences

It is often difficult to determine the preferences of individual patients, and patient preferences may change over time with changing circumstances. Less 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 [11–14]. Most patients have not completed advance written (instructive) directives, and a majority have not discussed preferences related to end-of-life care in advance [13]. Also knowledge and understanding of the patients’ 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 patients and their families.

1.5. 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.

1.6. 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 [1–6]. Exclusion of team members from this process may lead to dissatisfaction.

1.7. 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 is not sufficiently skilled in this aspect of care.

1.8. 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].
1.9. 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.

2. 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 utilisation 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/medico-legal 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 generalising data collected from a small sample size to the population as a whole.

Attempts have been made to understand both caregiver and families attitudes and knowledge about end-of-life care. Surveys and qualitative methods (focus groups) have been used extensively. As this data is frequently based on vignettes or questionnaires it may not be truly representative of the practice 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 emphasise, 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 is a great deal of data describing the process of withdrawal of life-support both from a mechanistic and an effect perspective. In essence this data emphasises 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 optimises and humanises 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 recognised that decisions to limit aggressive therapy are best made in a consensual/collaborative manner and should be communicated in a timely fashion to families and other members of the health care team [27]. Indeed, the limitations of life-sustaining
Table 1
Main north American and European epidemiological studies on end-of-life

<table>
<thead>
<tr>
<th>Year</th>
<th>Author</th>
<th>Reference</th>
<th>Type of study</th>
<th>Number of patients reviewed (died)</th>
<th>National/ multinational</th>
<th>Period of study</th>
<th>WH&amp;WD%</th>
<th>CPR initiated</th>
<th>Why decision made</th>
<th>Involvement</th>
<th>Major findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>1990</td>
<td>Knaus</td>
<td>18</td>
<td>France</td>
<td>Prospective</td>
<td>1191</td>
<td>National</td>
<td>1984</td>
<td>32%</td>
<td>1987–1988</td>
<td>51%</td>
<td>49%</td>
</tr>
<tr>
<td>1990</td>
<td>Smedira</td>
<td>19</td>
<td>US</td>
<td>Prospective</td>
<td>national (MC)</td>
<td>1996</td>
<td>51%</td>
<td>60%</td>
<td>Poor prognosis in 97%</td>
<td>10%</td>
<td></td>
</tr>
<tr>
<td>1996</td>
<td>Robert</td>
<td>20</td>
<td>France</td>
<td>Prospective</td>
<td>60%</td>
<td>National (MC)</td>
<td>1992–1993</td>
<td>90%</td>
<td>Poor prognosis in 97%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1997</td>
<td>Prendergast</td>
<td>21</td>
<td>US</td>
<td>Prospective</td>
<td>200</td>
<td>National (MC)</td>
<td>1994–1995</td>
<td>Mean of 48%*</td>
<td>MD &gt; 60%; Ns &lt; 20%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1997</td>
<td>Keenan</td>
<td>23</td>
<td>Canadian</td>
<td>Retrospective</td>
<td>419</td>
<td>National (MC)</td>
<td>1993–1994</td>
<td>70%</td>
<td>Poor prognosis in 97%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2000</td>
<td>McClean</td>
<td>2</td>
<td>Canadian</td>
<td>Retrospective</td>
<td>439</td>
<td>National</td>
<td>1988</td>
<td>45%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2001</td>
<td>Pochard</td>
<td>22</td>
<td>French</td>
<td>Prospective</td>
<td>208</td>
<td>National (MC)</td>
<td>1 month in 1999</td>
<td>50%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2001</td>
<td>Esteban</td>
<td>1</td>
<td>Spanish</td>
<td>Prospective</td>
<td>644</td>
<td>National (MC)</td>
<td>1996</td>
<td>34.30%</td>
<td>Physicians in 92%; family not involved in a third of patients</td>
<td>Whole team</td>
<td></td>
</tr>
<tr>
<td>2001</td>
<td>Ferrand</td>
<td>3</td>
<td>France</td>
<td>Prospective</td>
<td>1175</td>
<td>National</td>
<td>1997</td>
<td>67%</td>
<td>WH/WD practiced despite legal prohibition</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

WH = withholding; WD = withdrawing.
technology should be communicated soon after the patient’s admission to intensive care.

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 recognise these differences and not strive for equal ‘quantity’ but rather strive for exceptional ‘quality’ in end-of-life care.

3. 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, as well as wide variations between and within countries and between individual units is not in doubt, although some of the differences may be more apparent than real and recent evidence suggests that there has been some convergence in practice. To summarise, 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 organisation 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.

3.1. 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 lawsuits 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 is, 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
Benefit the patient. Similar views have been expressed regarding the patient’s care on the basis of what he or she considers will benefit him or her. Rather, the decision will be made by the clinician in charge of the treatment decision is not their right or their responsibility. The treatment decision is not their right or their responsibility.

Established by the British Medical Association, “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).

3.2. Religious and cultural influences

Most societies are increasingly multicultural and multiracial, with a diversity of religious beliefs, and deficiencies in end-of-life care tend to be more pronounced in ethnic minority populations [31]. Recognising 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 were 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 or Sweden [34].
Not only 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 generalisations, 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 termination 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. Recognising this, the US Institute of Medicine (1997) characterised 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].

3.3. Differences in the organisation of intensive care services

Substantial, largely unexplained variations in the organisation 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 organisational 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.

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 organisational influences [42].

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

4.1. 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 healthcare decisions; beneficence, healthcare should benefit the patient; non-maleficence, healthcare 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 unwillingness 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 a terminal patient’s family 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 agonising 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 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 judgement 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.

4.2. Decision-makers

4.2.1. 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 minimising 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 judgement” 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 stressed if excluded, has not been examined.

4.2.2. The health care team

4.2.2.1. 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 post-operative 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 their 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.

4.2.2.2. 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 in-
volvement 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.

4.2.2.3. Other team members. Other health care team members may also be valuable participants in the decision-making process. For example, respiratory 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].

4.3. The decision-making process

4.3.1. The ideal

A perceived dichotomy exists between the North American approach to end-of-life decision-making and 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 2/3 of the patients interviewed in an emergency ward preferred to have their family make healthcare 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 their health care decision-making. Also, laws governing patient autonomy has long been in existence in the USA and more recently enacted in Belgium and France, recognise the rights of patients to refuse care, even if death may ensue. Consent 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 on the extent of family involvement in decisions. In the USA 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 families about their loved ones’ 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 culture and religion, and to build a collaborative relationship with the family. Such meetings, when conducted in a standardised, 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 families on the patients’ 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]. Wherever 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 pre-morbid 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 so that there is 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 the cases [59], although adequate communication, as described later, 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 pre-determined interval of 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 rarely is 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 minimised 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 listening more [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 number 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 maximise 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 ones’ 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 minimised.

4.3.2. 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 ones’ 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 versus southern Europe [5], with those in the South being less likely to involve patients’ families 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 advocates 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.

5. 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:

- provides relief from pain and other distressing symptoms;
- intends neither to hasten nor postpone death;
- affirms life and regards dying as a normal process;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- 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...
Young doctors must be trained to deliver such informed, compassionate care. This must be imparted in medical school and during post-graduate 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 [56,68–70]. Doctors, young and old, must learn to speak to patients and family 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 to achieve a death with dignity. To quote Cicely Saunders [72]: “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”.

References


