Uncertainty in end-of-life care and shared decision making

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Since its inception over 50 years ago, intensive care has successfully restructured and enhanced the care of the most severely ill. Unfortunately, despite advances in the understanding and treatment of disease, some patients succumb, either as a natural progression of their disease or as a result of withholding or withdrawing intensive care support. Assessing the appropriateness of continuing life support is a difficult task for intensive care unit staff. The ability to maintain life in the face of outcomes such as death or a state unacceptable to the patient is a characteristic of modern intensive care; this has implications for patient suffering, respect for patient and family wishes, denial of resources to others, and costs.

A peaceful, pain-free death is an important part of good intensive care. Dunstan proposed that intensive care should be judged by the quality of life of those who survive rather than the number of lives saved, and by the quality of death of those in whose best interest it is to die.1 However, at the bedside, the decision to institute palliative care is difficult because of uncertainty in determining outcomes, managing unrealistic expectations and communicating effectively with the patients and families. In this article, we discuss uncertainty and how to manage it through shared decision making.

Uncertainty in medicine

Uncertainty surrounds complex judgements about diagnosis, treatment and prognosis. Cassell suggested that as clinicians gain more experience, the more they are beset by uncertainty.2 A hallmark of clinicians is the ability to tolerate uncertainty. In clinical practice, this is often managed by de-individualising the patients, denying uncertainty, redefining the problem to eliminate uncertainty, shrinking the problem to smaller dimensions, and recognising that present uncertainty will resolve in time.

Katz discussed doctors’ tendency to brush aside medical uncertainty.1 Failure to acknowledge uncertainty may result from simple denial, from traditional ideas about the ethical conduct of physicians, or from beliefs about the proper discharge of professional responsibilities. Katz believed that the quest for certainty may be futile, noting that the enormous and varied body of present knowledge may actually increase confusion.3 Beresford categorised clinical uncertainty into conceptual uncertainty (ie, the inability to apply abstract knowledge to concrete situations), technical or procedural uncertainty (ie, the absence of scientific data or practical skill) and personal uncertainty (ie, the lack of previous relationship with a patient and knowledge of their care wishes).4 Doctors need to understand and manage such uncertainty and the limitations it imposes on the reliability and validity of their clinical judgements.5,6 For doctors involved in end-of-life planning in the ICU, recognising and managing uncertainty is important and is an essential prerequisite for high-standard critical care.

Appropriateness of continuing treatment

Treatment is inappropriate if it will not lead to survival, is not in keeping with the patient’s wishes, or will not produce an outcome acceptable to the patient. However, quantifying the value, burdens and benefits of treatment is fraught with uncertainty. Prognostication in intensive care has some features (eg, patient’s illness severity, dependence on life support and rapidly changing clinical situation) that make it different from that in other disciplines. Even for senior doctors, prognostication of critically ill patients is difficult,7,9
but can be improved using objective measures, obtaining others’ opinions and achieving consensus.

**Objective measures**

Survival prediction can be improved by objective measures, such as severity-of-illness scoring systems. However, scoring systems do not exclude uncertainty. For example, the effect of influential higher-order variables (eg, the organisation of ICU) may not be captured, and earlier treatment outside ICU may have stabilised important physiological variables. There may also be significant differences in patient casemix, and the influence of subsequent improvements in delivery and application of critical care may be ignored. Finally, present scoring systems do not achieve a sensitivity that is high enough on which to base treatment limitation decisions for individual patients. Scoring systems are a useful adjunct but not a replacement for clinical decision making.

Agreement between clinicians about prognosis

To maintain equity of access to care, decisions to continue intensive care should be made as reliably and accurately as possible. Unfortunately, there is good evidence that, presented with the same clinical information, physicians will not always make the same judgement. Three sources of decision variation have been identified — attaching importance to different criteria, perceiving different information as relevant and interpreting the same information differently. Clinicians need to carefully collect and appraise evidence about prognosis and be honest with themselves and patients and their families about uncertainty and the limits of knowledge.

The importance, relevance, and meaning of clinical information is influenced by experience. Doctors who make ICU admission decisions tend to receive feedback only about the patients who were admitted, but it is important to appreciate that many patients refused ICU admission survive to leave hospital (51.8%, compared with 69.2% for admitted patients). This limited feedback on patient outcome will leave hospital (51.8%, compared with 69.2% for admitted patients) that many patients refused ICU admission survive to leave hospital. 

Five hundred and seventeen patients (62%) survived to 180 days. Clinicians’ prognoses were generally pessimistic, with a mean predicted survival of 49% at 180 days. For the fifth of patients with the poorest prognosis according to the clinician, the predicted survival rate was 10%, while the actual rate was 40%. It is likely that some patients who were denied admission to ICU might indeed have survived. Because of limitations of human memory and processing capability, explicit reinforcement of relevant information can be useful; the National Institute for Health and Clinical Excellence guideline on the management of chronic obstructive pulmonary disease exacerbations recommends seven items of information (ie, functional status, body mass index, requirement for oxygen when stable, comorbidities and previous ICU admissions, age and forced expiratory volume in 1 second) to be taken into account when assessing patient suitability for intubation and ventilation.

Consensus and second opinion

It is important that the patient’s interests are protected from random and unjustifiable decision making, and that uncertainty is minimised. With regard to withdrawal of organ support, there is a danger of clinical nihilism and outcome predictions becoming self-fulfilling prophesies. Wilkinson pointed out that self-fulfilling prophesies do not necessarily make treatment limitation decisions problematic. He added that clinicians need to carefully collect and appraise evidence about prognosis and be honest with themselves and patients and their families about uncertainty and the limits of knowledge.

In both the United Kingdom and Australia, the final responsibility for withdrawing or withholding life support rests with the ICU consultant, but the views of other clinical staff are sought and valued. Nursing staff will have established rapport with the patient’s family and may have a clearer idea of their perspective and wishes. The referring team will be able to offer insight into the usual outcome of similar patients. It is important to strive for consensus, and national guidelines on end-of-life care actively promote this. Consensus is also important as it will reduce uncertainty in the eyes of the family (see below).

Managing uncertainty with the family conference

The basic tool for effectively communicating the appropriateness of continuing intensive care and determining the optimal treatment plan is the family conference. The conference is an opportunity to explicitly manage remaining uncertainty about outcome and reduce uncertainty by establishing the patient’s wishes and the role that family members wish to play. Most of this can be achieved through shared decision making, the key components of
Box 1. Shared negotiation with the family

Provisioning medical information
- Discuss the nature of the decision. What is the essential clinical issue?
- Describe treatment alternatives. What are the clinically reasonable choices?
- Discuss the pros and cons of the choices. Pros and cons of the treatment choices?
- Discuss uncertainty. What is the likelihood of success of treatment?
- Assess family understanding. Is there a working understanding of the decision?

Eliciting patient values and preferences
- Elicit patient values and preferences. What is known about the patient’s medical preferences or values?

Exploring the family’s preferred role in decision making
- Discuss the family’s role in decision making. What role should the family play in making the decision?
- Assess the need for input from others. Is there anyone else the family would like to consult?

Deliberation and decision making
- Explore the context of the decision. How will the decision affect the patient’s life?
- Elicit the family’s opinion about the treatment decision. What does the family think is the most appropriate decision for the patient?

Clinical problem and outcome, and exploring options
Intensivists are generally good at describing the clinical problem. Clinical outcome is within the competence of medical staff as they are best placed to balance the burden (and treatment) of disease against survival (accepting variation in individual prognostic estimates). Survival has two important components: quality and duration. While quality of life is a uniquely personal attribute, the limitations of cognitive and physical function inflicted by critical illness that can impair subsequent quality of life are well recognised. 

Clinical problem

Eliciting patient values and preferences

Providing medical information

Exploring the family’s preferred role in decision making

Deliberation and decision making

Clinical problem and outcome, and exploring options

which include discussing the nature of the clinical problem and likely outcome, exploring ramifications of forthcoming decisions, establishing patient wishes and values, confirming family understanding of information, discussing preferred roles in decision making, and ultimately achieving agreement about treatment course (Box 1)17. Surrogate decision makers, either nominated as part of an advance care plan or self-selected from family and friends, are the normal contributors to the family conference.

White and colleagues outline the main methods of shared decision making as separating the people from the problem, focusing on interests rather than positions and generating options before setting an agreement that is based on objective criteria.17 Unfortunately, when measured in a sample of 51 decision-making conferences, only one met all these criteria. The most commonly covered was the clinical problem, while the least frequently addressed were the family’s role in decision making (ie, simple agreement or full engagement) and assessment of the family’s understanding. This would suggest that there is a need to improve clinician training and perhaps make family interviews more structured.

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The patient’s response to intensive care support over time provides supplementary information regarding outcome. For most critically ill patients, the clinical situation stabilises after ICU admission and gradually improves over the following days; most patients who die while critically ill do so relatively shortly after admission (median [interquartile range (IQR)] hospital stay 9 days [3–22 days] for non-survivors, compared with 16 days [9–33 days] for survivors21). Patients who initially fail to rally do very badly, and, unfortunately, some patients develop a devastating complication or relapse after an initial improvement. The rate of clinical improvement provides useful information on which to base an estimate of outcome. A multinational study demonstrated that decisions to withdraw and withhold treatment were rarely made until the fourth day of admission to ICU,22 which also correlated with surrogate acceptance of prognosis.23

Establishing the patient’s wishes

Irrespective of the seriousness of the condition, the presumption is that the patient is competent.24 Unfortunately, many ICU patients may be unable to satisfy the tests of understanding or capacity, of retaining information and of expressing a clear choice; less than 21% of ICU patients retain decision-making capacity.25 Although Cassell and colleagues found that a sick adult has the decision-making capacity of a 10-year-old child,26 patients in ICU who can communicate seem to make rational and sophisticated decisions despite possibly being in pain and in a stressful environment. The commonest stressors described by ventilated patients (dyspnoea, pain, anxiety and fear) are all important factors that influence patient thinking.27 Sedative drugs, tracheal intubation and artificial ventilation will further impair thinking and communication.

ICU staff have an obligation to follow patient wishes, but if these are unknown, treatment is offered based on best interests or substituted judgement. Best interests encompass a more holistic approach than just best medical interests, but establishing best interests can be challenging. More social or emotional end points are encapsulated within best interests and could be regarded as equivalent in deciding how to treat patients. An alternative is substituted...
judgement which tries to make the choice that the person themselves would have made, if they had the capacity to do so. It is a method of decision making used more commonly in the United States and Europe than in the UK. However, whichever method is used, it is vital that ICU staff avoid substituting their own value judgements.

Formulating an ICU management plan frequently requires the combined judgement of families and clinicians but this may introduce potential mismatch between the uncertain interests of the patient and the need to sustain life. Surrogates most frequently reduce uncertainty by providing valuable insight into the patient’s wishes, but occasionally they may have other agendas that influence their perspective.

Surrogate decisionmakers’ views may reflect their own health values rather than the values of those they represent.\textsuperscript{28,29} In a study of 298 patients, one-third of married participants did not choose their spouse as person responsible.\textsuperscript{30} There are inconsistent data, usually derived from studies using scenarios, that surrogates do not accurately understand patients’ wishes.\textsuperscript{31-34} A meta-analysis suggested that prior discussion between surrogate and patient did not necessarily improve the accuracy of surrogate prediction.\textsuperscript{35} Some jurisdictions, such as the New South Wales Guardianship Tribunal, define a decision-making hierarchy that may be at variance with patient’s wishes. Surrogate decision making may be consciously influenced by such factors as potential financial benefit or fear of caring for an invalid. Therefore, uncertainty may arise occasionally as to who best represents the patient and whether the information provided is accurate.

Whether the views expressed in advance are relevant to the current situation may also be uncertain. Many advance care directives contain the phrase “no reasonable chance” and leave the treating clinician and family to try to interpret what the patient meant by reasonable. The validity of a patient’s wishes can be expressed in varying levels of decreasing reliability:

- Level 1. A documented advance care plan relevant to the current situation which has been discussed with a nominated surrogate in a structured session.
- Level 2. An advance care plan relevant to the current situation.
- Level 3. Informal discussions about the patient’s wishes held between family and friends and the patient.
- Level 4. Family and friends’ belief that their knowledge of the patient allows them to determine what the patient would want.
- Level 5. The physician’s assessment based on limited personal knowledge but knowledge of what others in similar circumstances want.

An advance care plan and a surrogate who has been part of a decision-making process with a trained facilitator consistently leads to improved end-of-life care, satisfaction of families, less aggressive medical care, reduced stress and improved quality of life for bereaved families and earlier referral for hospice care.\textsuperscript{36} To work most effectively, care plans require five elements: trained facilitators, patient-centred discussions, involvement of the family, carefully filed documentation and engagement of the medical staff. Advance care plans appear not to change over time.\textsuperscript{37} However, without a care plan, patients may (and are at liberty to) change their minds; for example in SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments), 17% of control patients and 20% of intervention patients changed their resuscitation preferences to forgo cardiopulmonary resuscitation by the second week after enrolment.\textsuperscript{38} This may reflect indecision in the face of stressful and uncertain circumstances and/or the lack of time available for consideration of all the issues required to formulate a robust advance care plan.

Different religious and ethnic beliefs between countries are known to affect how end-of-life decisions are made.\textsuperscript{39} However, as society becomes more pluralist, differences between the patient and the clinical staff may cause problems when treating minority groups. There may be apprehension about being culturally inappropriate, inadvertently causing offence or appearing discriminatory or racist. If this is not recognised and managed, it may lead to uncertainty, disempowerment and inertia in practice.\textsuperscript{40} Irrespective of beliefs or other reasons, in the UK and Australia a patient or family cannot demand that a doctor administer a treatment that the doctor considers is contrary to the patient’s clinical needs.\textsuperscript{41}

**Practical certainty**

Hurwitz and Sheikh suggested that we need to revise attitudes towards medical errors.\textsuperscript{42} Complex systems or concepts, of which prognostication is one, are inherently subject to errors; an important goal in reducing errors is to disclose and discuss errors and potential errors rather than ignore or conceal them. Logan and Scott emphasised that doctors need to recognise that uncertainty is something they can share with their patients, especially if it relates to diagnosis and outcome.\textsuperscript{43} They suggest that persistent, masked, or denied uncertainty is often a greater cause of patient discomfort than having to cope with knowing the worst; open dialogue establishes a more honest relationship and may uncover previously unrecognised areas thereby reducing uncertainty.

Gillis and Tobin recommended a change in thinking regarding uncertainty in end-of-life care.\textsuperscript{44} They noted that from the time of Aristotle, it has been appreciated that the degree of certainty achievable in areas such as mathematics cannot be achieved in ethical discussion. They suggested that scientific...
certainty is not achievable and so practical certainty should be the goal. Practical certainty contrasts with the absolute certainty achievable in pure science and is being as certain as it is reasonable to be in the circumstances.

In the ICU at the end of life, practical certainty relies heavily on time and the collective wisdom of experienced physicians. Essentially, this involves prognostication based on objective evidence of likely outcome, preferably involving the collective wisdom of a number of clinicians, supported by the response of the patient to treatment over time. If this process is adhered to, it may be reasonable to say to patients and families that “we are as certain as we can possibly be”. Practical certainty can also be applied to determining patient’s wishes, where, in contrast to prognosis, the major source of information will be the family.

Awareness of uncertainty
To the uncertainty of doctors is added the uncertainty of families and surrogates. Families have to deal with strangers in whom they are expected to have confidence. The media reinforce the successes of medicine through fictional television dramas and advertising by industry; research “stories” may be geared to obtain funding. In addition, reported mishaps in hospitals and court cases regarding end-of-life decision dramas and advertising by industry; research “stories” may be geared to obtain funding. In addition, reported mishaps in hospitals and court cases regarding end-of-life decisions increase anxieties.

It is important to appreciate the patients’ and their families’ perspectives on uncertainty. Evans and colleagues canvassed the views of 179 surrogate decisionmakers. Eighty-seven per cent wanted physicians to discuss an uncertain prognosis because surrogates believed uncertainty was unavoidable, that physicians were the best source of accurate prognostic information, and that discussing uncertainty left room for hope, increased trust in the physician and allowed time to make difficult life support decisions. The minority who felt that discussions about uncertainty should be avoided were concerned that uncertain prognoses may be unnecessarily upsetting or that they should be told when the prognosis was more certain. Surrogates’ doubts about prognostic accuracy may reflect a belief that their god could alter the course of illness, a belief that predicting the future is inherently uncertain, and prior experiences of inaccurate or varying physician prognostications earlier in the patient’s admission. These attitudes emphasise the requirement to reach consensus about outcome before the discussions with the family.

There are limited data to suggest that more experienced ICU clinicians make more accurate prognoses. Senior ICU clinicians are likely to admit comparatively more patients to ICU. Barnato and colleagues used simulation to test the decision-making performance of senior medical staff (emergency physicians, hospitalists and intensivists) when faced with an elderly man with metastatic cancer. More experienced (presumably older) physicians erred on the side of initiating intensive care. The reasons for the aggressive stance taken by the more experienced physicians were not clear, but may relate to training and practice issues (such as being more attentive to patient and family requests, greater experience of unexpected patient survival) or personal issues (such as recognition of their own mortality or appreciation of inaccuracies of past predictions). Furthermore, it is not known whether this willingness to admit patients to ICU is matched by a willingness to consider limiting life support measures more readily.

Avoiding conflict
Unfortunately, conflict between the family and health care staff occasionally arises; these tend to be worst-case scenarios representing failure of communication and understanding by both parties. Conflict rarely arises spontaneously and usually results from a sequence of unfortunate circumstances or actions. There are several steps that can be taken to minimise the chances of serious disagreement.

Effective communication
Effective communication to improve family understanding needs consistent information delivery, earning trust and listening. Key constructs for effective communication at the family conference are shown in Box 2. These have been shown to be major determinants for families deriving benefit from end-of-life discussions. Part of earning trust is an open acknowledgement of prognostic uncertainty. It is important to simultaneously avoid conflict by dealing with issues such as loss of trust (eg, due to poor previous communication, failure to understand the patient’s perceived views, beliefs or wishes, unrealistic expectations), concern about care (eg, symptom relief being ignored once a “do not resuscitate” order is agreed, reduced nursing care once discharged from ICU), grief and guilt.

Conflict warning signs
Uncertainty and ineffective communication can cause or aggravate conflict. The circumstances under which conflict is more likely to arise include patients from small religious or ethnic groups, patients with a medical or nursing family member (who may be sometimes overseas), when medical consensus has not been achieved and when there is no advance care plan. The early signs of likely conflict are not well documented, but in our experience, circular conversations in which old issues and grievances are revisited while major issues are avoided are an early warning sign. The help of other parties, be they medical or non-medical, at this time may be beneficial.

Data from NSW suggest that late warning signs include increasingly unrealistic demands, accusations of negativ
conflicts are rarely resolved in ICU and lead to police involvement and refusal to accept brain death. By this stage, such conflicts are rarely resolved in ICU and lead to police involvement and refusal to accept brain death. By this stage, such conflicts are rarely resolved in ICU and lead to police involvement and refusal to accept brain death. By this stage, such conflicts are rarely resolved in ICU and lead to police involvement and refusal to accept brain death. By this stage, such conflicts are rarely resolved in ICU and lead to police involvement and refusal to accept brain death. By this stage, such conflicts are rarely resolved in ICU and lead to police involvement and refusal to accept brain death. By this stage, such conflicts are rarely resolved in ICU and lead to police involvement and refusal to accept brain death. By this stage, such conflicts are rarely resolved in ICU and lead to police involvement and refusal to accept brain death. 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