

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

Malcolm Fisher and Saxon Ridley

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.³ 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

ABSTRACT

Assessing the appropriateness of continuing life support is a difficult task for intensive care unit staff. Part of this difficulty relates to prognostic uncertainty and the varying reliability of clinical decisions. Uncertainty about prognosis is quickly recognised by patients and families, and can be a source of mistrust and potential conflict. We discuss the reasons for uncertainty and outline key measures to reduce and manage such uncertainty. Practical certainty, where the clinicians are as certain as they can be, with both prognostication and knowledge of patient wishes, may be an appropriate concept for physicians engaged in end-of-life decisions. It involves accurate prognostication, informed surrogates, advance care planning, time to assess response, and the collective wisdom of experienced clinicians. The family conference should develop an agreed plan through shared decision making. The collective wisdom of experienced health care workers with good communication skills and informed patient advocates increases the likelihood of achieving practical certainty and the best decisions. However, greater time and effort seems to be required to improve end-of-life care in the ICU.

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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.¹⁰

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 patients¹¹). This limited feedback on patient outcome will formulate and adjust decision rules held in long-term memory, and can lead to idiosyncratic beliefs about which patient characteristics relate to clinical outcomes. In hindsight, clinicians tend to remember information consistent with the final outcome while de-emphasising contradictory or ambiguous information. Knowing that a patient died or survived to discharge focuses attention on clinical features consistent with that outcome while other important features may be forgotten. Furthermore, a clinician's perception of uncertainty is strongly influenced by judgements that later in the patient's clinical course proved incorrect.

ICU physicians tend to be pessimistic about outcome and have concerns about the inappropriate use of technology. Wildman and colleagues compared the clinicians' prognoses in 832 patients aged over 44 years presenting with breathlessness, respiratory failure, or change in mental status due to an exacerbation of chronic obstructive pulmonary disease or asthma with the patients' 180-day

survival.¹² 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.¹³

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 prophecies. Wilkinson pointed out that self-fulfilling prophecies do not necessarily make treatment limitation decisions problematic.¹⁴ 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.^{15,16} 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**Providing 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?*

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 decisionmakers, 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.

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.¹⁸⁻²⁰ The challenge for ICU staff is to identify patients who are going to be overwhelmed in the short term by their acute illness, or perish during convalescence shortly after ICU or hospital discharge.

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 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.^{28,29} In a study of 298 patients, one-third of married participants did not choose their spouse as person responsible.³⁰ There are inconsistent data, usually derived from studies using scenarios, that surrogates do not accurately understand patients' wishes.³¹⁻³⁴ A meta-analysis suggested that prior discussion between surrogate and patient did not necessarily improve the accuracy of surrogate prediction.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 subconsciously 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.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.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.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.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.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.⁴¹

Practical certainty

Hurwitz and Sheikh suggested that we need to revise attitudes towards medical errors.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.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.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 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.⁴⁵ 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.²⁹ 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.⁴⁶ 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.⁴⁷ 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.⁴⁸ 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, or 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 negativity

Box 2. Key constructs of effective communication at the family conference

- Recognise the importance of uncertainty.
- Use appropriate language in the family conference — avoid “withdraw care” and “nothing more we can do”.
- Avoid discussion of odds. Families latch on to and concentrate on the given figure. When the risk of death is high and a treatment option is low-risk, it may be perceived as acceptable in spite of potential suffering.
- Provide familiar faces at family conferences and consistent information delivery. If rostering means the discussion leader is to leave, the family should be formally handed over to the new discussion leader and other participants such as nurses encouraged to continue attending.
- Earn trust by the family seeing the way the staff interact with each other and how they speak to and care for the patients.
- Explain early that the goal of treatment is to return the patient to health and if this is not possible alternatives need discussion.
- Give families written material regarding end-of-life care and intensive care management.
- Present prognosis as in terms of practical certainty — “we are as certain as we can be”.
- Encourage second opinions.
- Involve known supporters (eg, religious leaders/family doctors).

coupled with demanding care from particular staff only, provision of internet information regarding miracles and arguments for delays for a miracle or overseas family to arrive. This may progress to failure to attend conferences, requests for ban on morphine use, disregard of patient's wishes, personal threats or assault, threats of litigation and/or police involvement and refusal to accept brain death. By this stage, such conflicts are rarely resolved in ICU and lead to referral to hospital or statutory bodies, the media or courts. In the US, unfortunate legal cases have prompted certain states to draft what some might consider dubious legislature whereby the physicians' values override those of the family.⁴⁹

Conflict resolution

Nelson and colleagues identified unrealistic expectations as a major cause of problems at the end of life.⁵⁰ Other problems included inability of the family to participate, lack of advance care directives, family disagreement, no surrogate decisionmaker and, least frequently, disagreement between the family and the treating team. Most of these issues can be ameliorated by a properly conducted family conference. Procedural solutions for managing conflict have been introduced, especially in North America. Rivera and colleagues explored the effectiveness of bioethics committees by examining 100 consecutive patients (out of 331 referrals).⁵¹ The principal factor triggering the referral to the committee was an unreasonable expectation of improvement (58%) followed by fear of legal consequences (14%),

religion (9%), guilt (7%), family dissent (7%) and patient choice (5%). The ethics consultations were effective in 28 of 36 (77%) where a physician was primarily responsible and 31 of 61 (51%) when family was responsible. Involvement of elders or religious leaders and second opinions may help.

Conclusions

Families respect wisdom and leadership from those who have earned their trust through providing good treatment and communication early in the course of the illness. However, end-of-life decision making needs leadership to steer the discussions. ICU physicians can accomplish this by using practical certainty to recognise scientific uncertainty and reassure the family that they are as certain as they can be. Ensuring that all the key components of the family conference are discussed facilitates better understanding of all parties' perspectives. However, improving end-of-life decision making requires training and experience.⁵² The major challenge in providing better end-of-life care is changing the culture of individual establishments and clinicians. So far, efforts to do this have met very disappointing outcomes.⁵³

Competing interests

None declared.

Author details

Malcolm Fisher, Intensive Care Specialist,¹ and Clinical Professor²

Saxon Ridley, Consultant in Anaesthesia and Intensive Care³

¹ Intensive Care Unit, Royal North Shore Hospital, Sydney, NSW, Australia.

² University of Sydney, Sydney, NSW, Australia.

³ Glan Clwyd Hospital, Rhyl, United Kingdom.

Correspondence: fisherms@tpg.com.au

References

- 1 Dunstan GR. Hard questions in intensive care. *Anaesthesia* 1985; 40: 479-82.
- 2 Cassell EJ. The sorcerer's broom: medicine's rampant technology. *Hastings Cent Rep* 1993; 23: 32-9.
- 3 Katz J. Why doctors don't disclose uncertainty. *Hastings Cent Rep* 1984; 14: 35-44.
- 4 Beresford EB. Uncertainty and the shaping of medical decisions. *Hastings Cent Rep* 1991; 21: 6-11.
- 5 Choi BC, Jokovic A, Kay EJ, et al. Reducing variability in treatment decision-making: effectiveness of educating clinicians about uncertainty. *Med Educ* 1998; 32: 105-11.
- 6 Christensen C, Cottrell JJ, Murakami J, et al. Forecasting survival in the medical intensive care unit: a comparison of clinical prognoses with formal estimates. *Methods Inf Med* 1993; 32: 302-8.
- 7 Meadow W, Pohlman A, Frain L, et al. Power and limitations of daily prognostications of death in the medical intensive care unit. *Crit Care Med* 2011; 39: 474-9.

- 8 Christakis NA, Lamont E. Extent and determinants of error in physicians' prognoses in terminally ill patients: prospective cohort study. *BMJ* 2000; 320: 469-72.
- 9 Poses RM, De Saintonge DM, McClish DK, et al. An international comparison of physician's judgements of outcome rates of cardiac procedures and attitudes towards risk, uncertainty, justifiability, and regret. *Med Decis Making* 1998; 18: 131-40.
- 10 Kostopoulou O, Wildman M. Sources of variability in uncertain medical decisions in the ICU: a process tracing study. *Qual Saf Health Care* 2004; 13: 272-80.
- 11 Ridley S, Morris S. Cost effectiveness of adult intensive care in the UK. *Anaesthesia* 2007; 62: 547-54.
- 12 Wildman MJ, Sanderson C, Groves J, et al. Implications of prognostic pessimism in patients with chronic obstructive pulmonary disease (COPD) or asthma admitted to intensive care in the UK within the COPD and asthma outcome study (CAOS): multicentre observational cohort study. *BMJ* 2007; 335: 1132-4.
- 13 National Institute for Health and Clinical Excellence. Chronic obstructive pulmonary disease: management of chronic obstructive pulmonary disease in adults in primary and secondary care. London: NICE, 2010. <http://www.nice.org.uk/nicemedia/live/13029/49425/49425.pdf> (accessed Jan 2012).
- 14 Wilkinson D. The self-fulfilling prophecy in intensive care. *Theor Med Bioeth* 2009; 30: 401-10.
- 15 Intensive Care Society. Guidelines for limitation of treatment for adults requiring intensive care. London: Intensive Care Society, 2003. http://www.ics.ac.uk/intensive_care_professional/standards_and_guidelines/limitation_of_treatment_2003 (accessed Jan 2012).
- 16 Australian and New Zealand Intensive Care Society. Statement on withholding or withdrawing treatment. Melbourne: ANZICS, 2003. <http://www.anzics.com.au/publications-a-resources> (accessed Jan 2012).
- 17 White DB, Braddock CH 3rd, Bereckney S, Curtis JR. Toward shared decision making at the end of life in intensive care units: opportunities for improvement. *Arch Intern Med* 2007; 167: 461-7.
- 18 Broomhead LR, Brett SJ. Clinical review: Intensive care follow-up — what has it told us? *Crit Care* 2002; 6: 411-7.
- 19 Kaarola A, Tallgren M, Pettilä V. Long-term survival, quality of life, and quality-adjusted life-years among critically ill elderly patients. *Crit Care Med* 2006; 34: 2120-6.
- 20 Herridge MS. Long-term outcomes after critical illness. *Curr Opin Crit Care* 2002; 8: 331-6.
- 21 Harrison DA, Brady AR, Rowan K. Case mix, outcome and length of stay for admissions to adult, general critical care units in England, Wales and Northern Ireland: the Intensive Care National Audit & Research Centre Case Mix Programme Database. *Crit Care* 2004; 8: R99-111.
- 22 Cook DJ, Guyatt G, Rocker G, et al. Cardiopulmonary resuscitation directives on admission to intensive care unit: an international observational study. *Lancet* 2001; 358: 1941-5.
- 23 Prendergast TJ. Resolving conflicts around the end of life care. *New Horizons* 1997; 5: 62-71.
- 24 Ms B v An NHS Hospital Trust (2002) 65 BMLR 149.
- 25 Griffith L, Cook D, Hanna S, et al; Level of Care Investigators; Canadian Critical Care Trials Group. Clinician discomfort with life support plans for mechanically ventilated patients. *Intensive Care Med* 2004; 30: 1783-90.
- 26 Cassell EJ, Leon AC, Kaufman SG. Preliminary evidence of impaired thinking in sick patients. *Ann Intern Med* 2001; 134: 1120-3.
- 27 Thomas LA. Clinical management of stressors perceived by patients on mechanical ventilation. *AACN Clin Issues* 2003; 14: 73-81.
- 28 Vig EK, Taylor JS, Starks JS, et al. Beyond substituted judgement: how surrogates navigate end of life decision-making. *J Am Geriatr Soc* 2006; 54: 1688-93.
- 29 Zier LS, Burack JH, Micco G, et al. Doubt and belief in physician's ability to prognosticate during critical illness: the perspective of surrogate decision makers. *Crit Care Med* 2008; 36: 2341-7.
- 30 Lipkin KM. Brief report: identifying a proxy for health care as part of a routine medical inquiry. *J Gen Intern Med* 2006; 21: 1188-91.
- 31 Zettel Watson L, Ditto P, Danks JH, Smucker WD. Accuracy and perceived gender differences in the accuracy of surrogate decisions about life-sustaining medical treatment among older spouses. *Death Stud* 2008; 32: 273-90.
- 32 Marks MA, Arkes HR. Patient and surrogate disagreement in end of life decisions: 10 surrogate accurately predict patient's preferences? *Med Decis Making* 2008; 28: 524-31.
- 33 Shapiro SP. When life imitates art: surrogate decision-making at the end of life. *Top Stroke Rehabil* 2007; 14: 80-92.
- 34 Moorman SM, Carr D. Spouses effectiveness of end of life health care surrogate: accuracy, uncertainty and errors of overtreatment or undertreatment. *Gerontologist* 2008; 48: 811-9.
- 35 Shalowitz DI, Garret-Mayer E, Wendler D. The accuracy of surrogate decision makers. A systematic review. *Arch Intern Med* 2006; 166: 493-7.
- 36 Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care plans on end of life care in elderly patients: randomised controlled trial. *BMJ* 2010; 340: c1345.
- 37 Danis M, Garrett J, Harris R, Patrick DL. Stability of choices about life-sustaining treatments. *Ann Intern Med* 1994; 120: 567-3.
- 38 A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). *JAMA* 1995; 274: 1591-8.
- 39 Cohen S, Sprung CL, Sjøkvist P, et al. Communication of end of life decisions in European intensive care units — the Ethicus Study. *Intensive Care Med* 2005; 31: 1215-21.
- 40 Kai J, Beavan J, Faull C, et al. Professional uncertainty and disempowerment responding to ethnic diversity in health care: a qualitative study. *PLoS Med* 2007; 4: e323.
- 41 R (on the application of Burke) v General Medical Council [2005] EWCA Civ 1003, para 2.5. <http://www.bailii.org/ew/cases/EWCA/Civ/2005/1003.rtf> (accessed Jan 2012).
- 42 Hurwitz B, Sheikh A. Health care errors and patient safety. Oxford: Blackwell Wiley, 2009.
- 43 Logan RL, Scott PJ. Uncertainty in clinical practice: implications for quality and costs of health care. *Lancet* 1996; 347: 595-8.
- 44 Gillis J, Tobin B. How certain are you doctor? *Pediatr Crit Care Med* 2011; 12: 71-2.
- 45 Evans LR, Boyd EA, Malvar G, et al. Surrogate decision-makers' perspectives on discussing prognosis in the face of uncertainty. *Am J Respir Crit Care Med* 2009; 179: 48-53.
- 46 Ridley S. Analysis of consistency in ICU consultants' decision making in clinical practice. *J Intensive Care Soc* 2010; 11: 232-36.
- 47 Barnato AE, Hsu HE, Bryce CL, et al. Using simulation to isolate physician variation in intensive care unit admission decision making for critically ill elders with end-stage cancer: a pilot feasibility study. *Crit Care Med* 2008; 36: 3156-63.
- 48 McDonagh JR, Elliot TB, Engleburg RA, et al. Family satisfaction with family conferences about end of life care in the intensive care unit: increased proportion of family speech is associated with increased satisfaction. *Crit Care Med* 2004; 32: 1484-8.
- 49 Truog RD. Tackling medical futility in Texas. *N Engl J Med* 2007; 357: 1-3.
- 50 Rivera S, Kim D, Garone S, et al. Motivating factors in futile clinical interventions. *Chest* 2001; 119: 1944-7.
- 51 Nelson JE, Angus DC, Weissfeld LA, et al; Critical Care Peer Workgroup of the Promoting Excellence in End-of-Life Care Project. End-of-life care for the critically ill: a national intensive care unit survey. *Crit Care Med* 2006; 34: 2547-53.
- 52 Murphy BF. What has happened to clinical leadership in futile care discussions? *Med J Aust* 2008; 188: 418-9.