How do you decide when to withdraw life support?

See Online for a podcast discussion of the withdrawal of life support

A primary goal of intensive and critical care medicine is to raise standards of care and improve outcomes for patients. But when non-responsive patients are unlikely to make a meaningful recovery, difficult decisions have to be made. Decision-making is influenced by many factors: ethical, economic, cultural, legal, and the wishes of the family. When there is overwhelming evidence that further treatment or keeping the patient alive with mechanical assistance is prolonging unnecessary suffering, how can this situation be explained to distressed family members? The terminology is

With most intensive care unit (ICU) patients now dying as the result of a decision to withhold or withdraw life-sustaining therapies, there is continuing debate and discussion about how this end-of-life process should be managed. In Belgium, euthanasia has been legal since 2002, allowing patients in certain carefully defined situations and under strict conditions to request a physician to perform euthanasia. However, this law does not apply to most ICU patients, who are generally not in a position to request euthanasia, and the legalities of end-of-life practices are less clearly defined, particularly in terms of administering drugs that can hasten death. To acknowledge and support current practice in Belgium, and indeed in other countries, the Belgian Society of Intensive Care has stated that shortening the dying process with use of medication, such as analgesics or sedatives, may sometimes be appropriate, even in the absence of discomfort, and can actually improve the quality of dying. In a recent survey of physicians certifying deaths in Belgium, about one fourth of all deaths were listed as being preceded by intensified alleviation of pain and other symptoms with the use of drugs, with possible shortening of life. Patient and family input is an important aspect of end-of-life decision-making in Belgium, but final decisions remain the responsibility of the doctor in charge, supported by a consensus within the ICU team. The World Federation of Societies of Intensive and Critical Care Medicine has a task force working on these issues. We can only say that the attitudes are extremely variable around the globe, so that it is difficult to find common values—perhaps the only consensus we could reach is around the important principle of proportionality of care, that should be applied everywhere. The concept of futile therapy should be abandoned, because it is inadequate and potentially misleading. We are working on the establishment of patterns for different regions, so that people could recognise themselves in one or another of these patterns.

Jean-Louis Vincent, Erasmus University Hospital, Brussels, Belgium, and President, World Federation of Societies of Intensive and Critical Care Medicine

In Israel as in most other countries, the physician decides when the patient will most likely die and life-sustaining treatments should be limited. What is very different to other countries is that life-sustaining therapies are not withdrawn. This is based on culture, religion, and law. The Israeli Terminally Ill Law 2005 prohibits stopping continuous life-prolonging treatments, but allows stopping intermittent life-prolonging therapies. Discontinuing intermittent life-sustaining therapies is regarded as omitting a therapy rather than withdrawal. The Law is based on Halacha or Jewish law where the value and sanctity of human life is infinite and beyond measure. Although the omission of life-sustaining treatments is allowed, an act that actively and intentionally shortens life is prohibited. The withdrawal of a ventilator, which is considered a continuous form of therapy, shortens life and is forbidden. Halacha considers that not only the ends have to be morally acceptable, but also the means. The Law also regards fluids and food as basic needs and not treatments, requires physicians to care for patients and families, considers palliative care as a citizen's right, and requires that any controversies are taken to ethics committees, not the courts. Decisions are based on the autonomous wishes of the patient, which are based on advance medical directives, the appointment of a surrogate decision maker, and testimony of an incompetent dying patient's wishes by family members or close friends.

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In the USA, and in most of the developed world, the majority deaths in the ICU are preceded by a decision to withhold or withdraw life-sustaining treatments. It is often commented that there is tremendous variability between countries. However, there is tremendous variability from ICU to ICU within countries (including the USA and England) and even from physician to physician; variability that is not explained by patient, family, or ICU characteristics. In fact, there is as much variability within countries and ICUs as between countries. The basis for the decision to withdraw life support should depend on patients' and families' goals and preferences as well as physicians' perspectives. Ideally, we should use the full spectrum of decision-making—from parentalism (doctor decides) through to shared decision-making to autonomy (patient or family decide). Where we are on this spectrum should be determined by the patient's prognosis, by the treatments that are available, and by the patient or family preferences for the role they choose to play in decision-making.

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As prognosticators and communicators, neurologists are neither unhinged optimists nor paralysing doomsayers. Acute brain injury is often a major setback in critically ill patients and a tenable reason to de-escalate care. Such a decision is straightforward when catastrophic neurological illness—often a severe diffuse cortical, diencephalic, or brainstem injury—occurs in a patient whose wishes are known. The expectation that the patient will lack cognition, autonomy, and dignity can determine resuscitative measures. In the USA, decisions are ideally reached after multiple discussions using a shared decision-making model. Disputes about futility of care can often achieve a conciliatory solution after carefully conducted family conferences. Yet, irrational hope or mistrust can result in continuation of care despite very poor prognosis. Legal fear and complacency can drive this decision. Lacking alternatives such as adjudicating hospital tribunals, disputes might have to be litigated in court.

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In South Africa, most of the population is served by the primary-care-orientated, state-run health system, which has proportionally few ICU beds—mainly in regional or academic hospitals. Decisions to withdraw life support are most often initiated by the intensivist in charge and are usually based on futility. Functional independence is an important outcome as long-term care facilities are minimal. Limited ICU facilities does affect decision making. After ICU team consensus, family assent, but not formal consent, is sought. Families largely trust the doctors and despite the culturally diverse population, religious objection is rare. Challenges include absent families due to distance, language barriers, as well as families in which male-dominated clan elders need to be consulted. There is no formal legal basis for end-of-life decisions, but the courts are guided by what medical peers would regard as reasonable. Euthanasia is illegal. In the health-insurance-funded private sector, most critically ill patients are managed by non-intensivists in open ICUs. Decisions to withdraw life support are made much later in the course of illness and may only be considered when there is medical aid failure.

Lance Michell, Division of Critical Care, University of Cape Town, Cape Town, South Africa

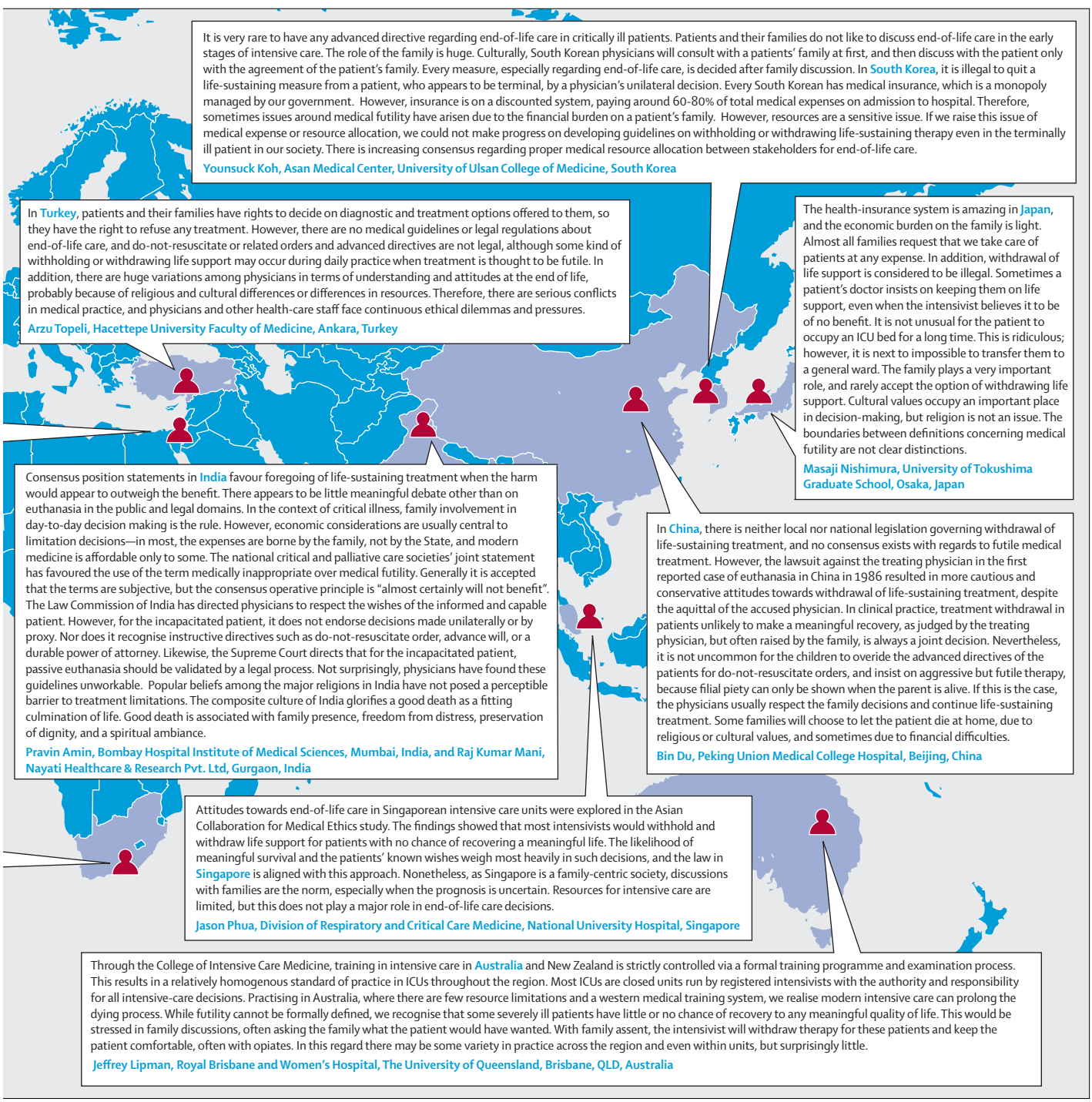
In Argentina, physicians base the clinical decision to withdraw life support on the history of the disease, which means how widespread it is, number of treatments, success of these different approaches, impact of treatment on the quality of life, patient expectation, dignity, and family and patient's feelings and beliefs. This decision would be made following failure of the treatment that had been based on the best clinical evidence, and takes account of the limitations of futile interventions where physicians are faced with the boundaries of overtreatment. Ideally, at this point, the physician who personally followed up the case and spoke to both the patient and relatives should be involved. There are no specific guidelines in our country to instruct us on this matter. I believe that such guidelines would facilitate the approach to the decision; however, when dealing with such a delicate situation, personal decisions must be respected. The philosophy in Argentina is to use all resources available, but this notion must be weighed against the potential harm of overtreatment. The best results are obtained when the decisions are made collaboratively, with the primary physician, intensivists, and the family.

Nestor Wainsztein, FLENI Institute, Buenos Aires, Argentina

changing—for example, medical futility is generally regarded as an inadequate term in this setting, and consensus around the world has not yet been reached. Finally, technology is advancing and expectations around life-saving interventions are shifting, influenced by the media and the internet.

We asked experts from around the world on what basis—when, and by whom—is the decision made to withdraw life support when the patient is unlikely to make a meaningful recovery? Their answers are shown in the map below and we also discuss the issues in an accompanying podcast. What do you think? Comments are welcome via @LancetRespirMed on Twitter or on *The Lancet*'s Facebook page.

Jules Morgan



It is very rare to have any advanced directive regarding end-of-life care in critically ill patients. Patients and their families do not like to discuss end-of-life care in the early stages of intensive care. The role of the family is huge. Culturally, South Korean physicians will consult with a patients' family at first, and then discuss with the patient only with the agreement of the patient's family. Every measure, especially regarding end-of-life care, is decided after family discussion. In South Korea, it is illegal to quit a life-sustaining measure from a patient, who appears to be terminal, by a physician's unilateral decision. Every South Korean has medical insurance, which is a monopoly managed by our government. However, insurance is on a discounted system, paying around 60-80% of total medical expenses on admission to hospital. Therefore, sometimes issues around medical futility have arisen due to the financial burden on a patient's family. However, resources are a sensitive issue. If we raise this issue of medical expense or resource allocation, we could not make progress on developing guidelines on withholding or withdrawing life-sustaining therapy even in the terminally ill patient in our society. There is increasing consensus regarding proper medical resource allocation between stakeholders for end-of-life care.

Younsuck Koh, Asan Medical Center, University of Ulsan College of Medicine, South Korea

In Turkey, patients and their families have rights to decide on diagnostic and treatment options offered to them, so they have the right to refuse any treatment. However, there are no medical guidelines or legal regulations about end-of-life care, and do-not-resuscitate or related orders and advanced directives are not legal, although some kind of withholding or withdrawing life support may occur during daily practice when treatment is thought to be futile. In addition, there are huge variations among physicians in terms of understanding and attitudes at the end of life, probably because of religious and cultural differences or differences in resources. Therefore, there are serious conflicts in medical practice, and physicians and other health-care staff face continuous ethical dilemmas and pressures.

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The health-insurance system is amazing in Japan, and the economic burden on the family is light. Almost all families request that we take care of patients at any expense. In addition, withdrawal of life support is considered to be illegal. Sometimes a patient's doctor insists on keeping them on life support, even when the intensivist believes it to be of no benefit. It is not unusual for the patient to occupy an ICU bed for a long time. This is ridiculous; however, it is next to impossible to transfer them to a general ward. The family plays a very important role, and rarely accept the option of withdrawing life support. Cultural values occupy an important place in decision-making, but religion is not an issue. The boundaries between definitions concerning medical futility are not clear distinctions.

Masaji Nishimura, University of Tokushima Graduate School, Osaka, Japan

Consensus position statements in India favour foregoing of life-sustaining treatment when the harm would appear to outweigh the benefit. There appears to be little meaningful debate other than on euthanasia in the public and legal domains. In the context of critical illness, family involvement in day-to-day decision making is the rule. However, economic considerations are usually central to limitation decisions—in most, the expenses are borne by the family, not by the State, and modern medicine is affordable only to some. The national critical and palliative care societies' joint statement has favoured the use of the term medically inappropriate over medical futility. Generally it is accepted that the terms are subjective, but the consensus operative principle is "almost certainly will not benefit". The Law Commission of India has directed physicians to respect the wishes of the informed and capable patient. However, for the incapacitated patient, it does not endorse decisions made unilaterally or by proxy. Nor does it recognise instructive directives such as do-not-resuscitate order, advance will, or a durable power of attorney. Likewise, the Supreme Court directs that for the incapacitated patient, passive euthanasia should be validated by a legal process. Not surprisingly, physicians have found these guidelines unworkable. Popular beliefs among the major religions in India have not posed a perceptible barrier to treatment limitations. The composite culture of India glorifies a good death as a fitting culmination of life. Good death is associated with family presence, freedom from distress, preservation of dignity, and a spiritual ambiance.

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In China, there is neither local nor national legislation governing withdrawal of life-sustaining treatment, and no consensus exists with regards to futile medical treatment. However, the lawsuit against the treating physician in the first reported case of euthanasia in China in 1986 resulted in more cautious and conservative attitudes towards withdrawal of life-sustaining treatment, despite the aquittal of the accused physician. In clinical practice, treatment withdrawal in patients unlikely to make a meaningful recovery, as judged by the treating physician, but often raised by the family, is always a joint decision. Nevertheless, it is not uncommon for the children to overide the advanced directives of the patients for do-not-resuscitate orders, and insist on aggressive but futile therapy, because filial piety can only be shown when the parent is alive. If this is the case, the physicians usually respect the family decisions and continue life-sustaining treatment. Some families will choose to let the patient die at home, due to religious or cultural values, and sometimes due to financial difficulties.

Bin Du, Peking Union Medical College Hospital, Beijing, China

Attitudes towards end-of-life care in Singaporean intensive care units were explored in the Asian Collaboration for Medical Ethics study. The findings showed that most intensivists would withhold and withdraw life support for patients with no chance of recovering a meaningful life. The likelihood of meaningful survival and the patients' known wishes weigh most heavily in such decisions, and the law in Singapore is aligned with this approach. Nonetheless, as Singapore is a family-centric society, discussions with families are the norm, especially when the prognosis is uncertain. Resources for intensive care are limited, but this does not play a major role in end-of-life care decisions.

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Through the College of Intensive Care Medicine, training in intensive care in Australia and New Zealand is strictly controlled via a formal training programme and examination process. This results in a relatively homogenous standard of practice in ICUs throughout the region. Most ICUs are closed units run by registered intensivists with the authority and responsibility for all intensive-care decisions. Practising in Australia, where there are few resource limitations and a western medical training system, we realise modern intensive care can prolong the dying process. While futility cannot be formally defined, we recognise that some severely ill patients have little or no chance of recovery to any meaningful quality of life. This would be stressed in family discussions, often asking the family what the patient would have wanted. With family assent, the intensivist will withdraw therapy for these patients and keep the patient comfortable, often with opiates. In this regard there may be some variety in practice across the region and even within units, but surprisingly little.

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