

Withdrawing life support and resolution of conflict with families

Jenny Way, Anthony L Back, J Randall Curtis

What is the best way for the intensive care team to work with a family to decide on a plan of care when withdrawing or withholding life support?

Department of
Medicine,
University of
Washington, Seattle,
WA 98195, USA

Jenny Way
*resident in internal
medicine*

Anthony L Back
*associate professor of
medicine*

J Randall Curtis
*associate professor of
medicine*

Correspondence to:
J R Curtis, Division
of Pulmonary and
Critical Care
Medicine,
University of
Washington,
Harborview
Medical Center,
Box 359762, 325
Ninth Avenue,
Seattle, WA
98104-2499, USA
jrc@u.washington.edu

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A high proportion of deaths in intensive care occur after withdrawal or withholding of life support. In a survey of critical care physicians, 85% of respondents had withheld or withdrawn life support in the preceding year.¹ A US study showed a large increase in the proportion of deaths in intensive care that were preceded by a decision to withhold or withdraw life support, from 50% in 1987-88 to over 90% in 1992-93.² In many countries, most deaths in intensive care are preceded by a decision to withdraw or withhold life support,^{3 4 w1-w4} although the proportion of deaths preceded by withdrawal versus withholding varies.⁴

Although limitation of life support before death is common in most intensive care units, there are wide variations in approaches to end of life care.^{5 6 w1 w5 w6} In a survey of 131 intensive care units in the United States, the proportion of deaths in which life support was withheld varied from 0% to 67% and the proportion of deaths after withdrawal of life support varied from 0% to 79%.⁵ These wide variations suggest the need for increased consensus on best practices for managing death in intensive care units. In this article, we review the empirical research that can guide physicians in deliberations over whether to withdraw life support, maximising patient and family involvement in the decision making process, and negotiating conflicts that may arise.

Methods

We performed literature searches with PubMed using the index terms for critical care ("critical care" or "intensive care" or "mechanical ventilation") and palliative care ("palliative care" or "end of life"). This gave 493 citations. We also included the index term "futility" in combination with the critical care terms, yielding 227 citations. We reviewed all abstracts and selected relevant, research based articles.

How are decisions made concerning withholding or withdrawing life support?

Clinicians and families make most of the decisions about life support in intensive care as less than 5% of patients are able to communicate with clinicians at the time.² When facing potential mental incapacitation,

Summary box

Many deaths in intensive care occur after withdrawing or withholding life support

Clinicians and families generally make the decision as most patients are too ill to participate, but who takes the lead role varies greatly

Conflict about withholding or withdrawing life support is common between clinicians and families and negotiation of these conflicts requires good communication skills

Good communication by intensive care physicians may shorten the dying process

Withdrawal of life support is a clinical procedure that requires good medical skills, cultural sensitivity, attention to ethical principles, and close collaboration with patients' families

90% of patients prefer family members to act as the decision makers and request that decisions be made in conjunction with their physicians.⁷ Unfortunately, few patients have ever discussed their resuscitation preferences with a family member,^{8 w7} and decisions by surrogates may not accurately reflect patients' preferences.⁹

Physicians also have poor understandings of patients' preferences, and most patients do not discuss their preferences with their physicians.¹⁰ Physicians' predictions of their patients' preferences for resuscitation are only moderately better than chance.^{11 w8} In addition, some physicians make inaccurate assumptions about resuscitation preferences based on a patient's age or quality of life.^{11 w9}

Another complication of the decision making process is that patients want proxy decision makers to use their judgment rather than be bound by the specifics of advance directives. In one study, 78% of patients stated that if their prior preferences differed from a decision made by their family and physician, they would want the family and physician's decision followed.¹² These limitations of advance directives and



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surrogate decision making highlight the importance of clinicians' ability to listen to and understand family concerns and skilfully negotiate treatment decisions.

How can conflicts between clinicians and families be negotiated?

Conflict surrounding decision making in intensive care units is common. Conflict can arise about issues such as communication styles, interpersonal interactions, and pain control as well as about treatment decisions.¹³ ^{w10} One study of intensive care patients for whom withdrawal of life support was considered found that conflict occurred between staff and family in 48% of cases, among staff in 48%, and among family members in 24%.¹³

The evidence on the best way to resolve conflicts suggests that communication, negotiation, and consensus building are the most important tools. Physicians use varying communication and negotiation strategies to resolve conflicts with dying patients.¹⁴ The most common approach, listed by 71% of physicians in one study, was directly educating and negotiating with patients about potential misunderstandings. Less common ways of dealing with conflict included deferring to patient requests for benign or uncomplicated treatments (34%), obtaining assistance of other family members (16%), and referring to other physicians for provision of disputed care (9%). Conflict can be constructive, uncovering differences in values and legitimate concerns that have been inadequately discussed. Improved communication about goals, prognoses, and treatment options will successfully resolve most conflicts and may minimise unrealistic requests by patients or families.^{w11 w12}

What is the role of futility in medical decision making?

In the case described in box 1, clinicians were frustrated with what they perceived to be the family's requests for "futile" care. In caring for critically ill patients, situations often arise in which further life sustaining treatments have a very low likelihood of success. At this point, further intervention may be described as futile, and clinicians may feel strongly that life sustaining therapy should be stopped. In 1991, the American Thoracic Society defined a life sustaining intervention as futile "if reasoning and experience indicate that the intervention would be highly unlikely to result in a meaningful survival for that patient."¹⁵ Despite cogent descriptions of the potential value of this concept in medical decision making,^{16 w13} controversy exists about what constitutes a futile intervention.¹⁷ Concern has been raised that physicians could abuse this principle by making unilateral judgments about the value of life.^{w14}

Most of the literature on medical futility examines the ethical and legal aspects rather than its use in clinical practice. One US study showed that even though physicians believe that futility often applies in "do not resuscitate" orders, they do not use the principle unilaterally in the absence of patient or surrogate concurrence.¹⁸ However, physicians were often inconsistent in their thinking about futility: in one third of cases, physicians applied the principle in situations where

they believed there was a greater than 5% chance of successful outcome.¹⁸

If the medical futility rationale is part of physicians' decision making processes, it should be clearly defined and supported by published data. Any determination of futility should be discussed with the patient or family members. In most cases, patients or families will agree^{2 w15} and may appreciate not having to choose to forego a treatment that is not indicated.¹⁹ However, if patients or families do not agree, the American Medical Association recommends a process be initiated to reconcile differences and that care be continued until reconciliation is achieved.²⁰

How competent are physicians at communicating with family members?

Families of critically ill patients consistently rate communication with intensive care clinicians among their most important concerns—more important even than clinical skills.^{w16} Studies examining the needs of relatives of intensive care patients indicate that the most important needs relate to communication and include having questions answered honestly, understanding the diagnosis and prognosis, and having information explained in understandable terms.²¹ However, physicians are often poor at discussing end of life issues, and even when communication occurs, it is often ineffective. A study evaluating physician-family meetings found that 54% of family members had not understood basic features of the diagnosis, prognosis, or treatment.²² Research on discussions of resuscitation status with hospital patients noted that physicians spend 75% of the time talking and miss important opportunities to allow patients to discuss their personal values and goals of therapy.²³

Few studies provide empirical evidence to guide clinicians on improving communication. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT) showed that a nurse led communication intervention had no effect on the care that dying patients received in intensive care.²⁴ Another study, however, found that a standardised, multidisciplinary family conference led by an attending physician that focused on goals and outcomes of life support resulted in an earlier transition to palliative care and reduced length of stay in intensive care for dying patients.²⁵ This study

Box 1 Illustrative case

Ms R, a 52 year old woman with severe rheumatoid arthritis and chronic immobility, was brought to the emergency department. Her health was poor, although stable, until the morning of admission, when she became disoriented and lethargic. She was admitted to intensive care, where she was treated for septic shock secondary to decubitus ulcers and for acute renal failure. On the day after admission she was requiring increasing doses of vasopressor drugs and developed acute respiratory distress syndrome. Some members of the intensive care team became increasingly concerned about the "futile" care they felt they were providing. The patient's family requested that the medical team "do everything" to keep her alive.
See box 2 for follow up.

suggests that improving communication with families can improve the quality of end of life care. A better understanding of families' needs and concerns may help clinicians to communicate more effectively.²⁶

What is the best way to withdraw life support?

The goal of withdrawing life support when death is expected is to remove treatments that are no longer desired or indicated and that do not provide comfort to the patient. Any treatment may be withheld or withdrawn, and most ethicists concur that there is no difference between withholding or withdrawing life supportive treatments.^{15 w17 w18} Many clinicians, however, feel more comfortable withholding rather than withdrawing treatments.^{w19}

The withdrawal of life sustaining treatments is a clinical procedure and therefore deserves the same preparation and expectation of quality as other procedures. Informed consent should be obtained and should include honest, caring, and culturally sensitive communication with family members, explanations of how interventions will be withdrawn, strategies for assessing and ensuring comfort, information about the patient's expected length of survival, and solicitation of feedback and strong preferences about end of life care.^{27 28 w6 w20} Time should be spent discussing, understanding, and accommodating cultural and religious perspectives.²⁹ An explicit plan for withdrawing care and handling complications should be formulated: the patient should be in the appropriate setting with irrelevant monitoring removed; the process should be carefully documented, including the reasons for increasing sedation; and outcomes should be evaluated to improve the quality of care.

Evidence suggests that dying patients' physical and emotional suffering is inadequately treated in intensive care units.^{30 w21} In SUPPORT, 40% of patients who died with acute respiratory failure and sepsis had severe pain and dyspnoea during the last three days of life.³¹ A study of cancer patients in intensive care showed a high burden of pain and other symptoms.³² Some clinicians consciously provide inadequate treatment for pain, even when withdrawing life support, because they fear hastening death.^{w6} However, current guidelines recommend placing a high priority on adequate symptom control using a combination of morphine or other narcotic with a benzodiazepine, continually infused



Most deaths in intensive care occur after a decision to withdraw or withhold life support

Box 2 Case follow up

The intensive care team arranged for a conference with the family. The attending physician asked the family to describe their understanding of the patient's condition. The family was far more optimistic than her physicians, thinking she had a 50% chance of recovery to her former state of health. The attending physician then asked the family to tell the team what Ms R was like as a person. The team learnt that she had always been full of energy and ready and eager to take on all challenges. They were thus able to appreciate her relatively good quality of life and role in her family.

The team then explained that Ms R's poor underlying health and immune suppression meant that she was unlikely to recover from the progressive septic shock. They explained that high quality medical care is defined both by improvement in health and, when improvement is not possible, by ensuring comfort. The family was unaware that most deaths in intensive care occur after withdrawing or withholding life support and, with that information, began to develop more trust. The team reassured the family that they had time to think everything over and that life support would continue for as long as the family believed it was what Ms R would want. They emphasised that withdrawal of life support did not mean withdrawal of medical and nursing care and that her pain and other symptoms would continue to be monitored and treated. The family felt supported by the team and relieved that they had not been pressured into accepting withdrawal of life support.

Ms R remained critically ill with multiple organ dysfunction syndrome and showed no significant improvement despite maximal therapy. After several days, the family decided that Ms R would not have wanted ongoing life support in this situation. The team explained the process of withdrawing life support. They informed the family that she would be unlikely to survive for more than an hour after withdrawal, although occasionally patients survive longer. The team also asked about spiritual needs and the family requested a chaplain.

Routine investigations were discontinued and all drugs were stopped except for morphine and lorazepam. Morphine and lorazepam were titrated to comfort during terminal ventilator discontinuation. Ms R's family returned to the bedside after her extubation and she died within 30 minutes. A chaplain was with the family when she died.

and titrated until the patient stops showing expressions of discomfort, including grimacing, agitated behaviour, and autonomic hyperactivity.³³ Specific circumstances may also justify the use of barbiturates, haloperidol, or propofol.^{w22}

Minimising distress for the patient and family

Once a decision is made to withdraw life sustaining treatments, the time course of withdrawal should be determined by the potential for discomfort as treatment is stopped. The only rationale for tapering life sustaining treatment is to allow time to control patients' symptoms. There is usually no need to taper pressor drugs, antibiotics, nutrition, or most other critical care treatments.

Mechanical ventilation is one of the few life support treatments that often cannot be stopped abruptly. The common approach to stopping ventilation (often called rapid terminal weaning) is gradually

to reduce the fractional inspired oxygen concentration to room air and ventilatory support to zero with anticipatory dosing of narcotics as needed for patient comfort. The patient is then placed on a T-piece with humidified air or extubated. Since the term “weaning” suggests the goal is independent spontaneous ventilation, we prefer the phrase “terminal ventilator discontinuation.” Limited data exist on whether patients should be extubated. Studies have found no significant difference in patient comfort,^{27 w23} but these studies lack power to detect clinically important differences. Terminal ventilator discontinuation may unnecessarily prolong dying if various steps are prolonged.^{w6} The transition from full ventilatory support to T-piece or extubation should take no more than 15-30 minutes.^{28 w24} Families should be warned that death, although expected, is not certain and that the timing can vary.

Neuromuscular blockers serve no therapeutic purpose during withdrawal of life support.^{33 w25-w27} Although paralytic drugs can ease the family's distress by making the dying patient seem comfortable,^{w25} they may increase suffering by preventing clinicians from adequately assessing patient discomfort. Paralytic drugs should therefore be stopped before life sustaining therapies are withdrawn and time given for the drug to clear. Nonetheless, 6% of physicians in the Society of Critical Care Medicine report using neuromuscular blockers at the end of life, at least occasionally,^{w6} and one study showed 9% of patients received neuromuscular blockers during withdrawal of life support.³⁴

The families' emotional reactions and needs also need to be anticipated. Families may believe they are causing the patient's death by agreeing to withdraw life support. Feelings of guilt should be explored directly and discussed openly. Relatives may feel less burdened by guilt if physicians strongly recommend that life support be withdrawn rather than asking the family to make the decision. Focusing the family on what the patient would want rather than what the family wants may also reduce the family burden. Other family and staff members (nurses, social workers, chaplain) can be enlisted to provide support, and the family should be asked if a priest or other religious adviser should be called before interventions are withdrawn. Many relatives report that the presence of clergy at the time of withdrawing life support is reassuring.^{w10}

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Promoting Excellence In End-Of-Life Care (www.promotingexcellence.org)—an organisation dedicated to improving the health care of dying people

Primer on critical care for patients and their families (www.thoracic.org/assemblies/cc/ccprimer/mainframe2.html)—information from the critical care assembly of the American Thoracic Society

Society of Critical Care Medicine (www.sccm.org)

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