

Dying Patients in the Intensive Care Unit: Forgoing Treatment, Maintaining Care

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OBJECTIVE: To determine the frequency of forgoing treatment and maintaining care in dying patients in the intensive care unit (ICU). DESIGN: Retrospective study. SETTING: A 100-bed tertiary care ICU. PATIENTS: All patients who died in the ICU during a 12-month period. MEASUREMENTS AND MAIN RESULTS: Of 1,000 patients who died in the ICU, 100 (10%) were excluded because they were not in the ICU at the time of death. Of the 900 patients who were in the ICU at the time of death, 450 (50%) had forgoing treatment and 450 (50%) had maintaining care. The frequency of forgoing treatment and maintaining care was similar in patients who were in the ICU at the time of death and those who were not in the ICU at the time of death. CONCLUSIONS: Forgoing treatment and maintaining care are common in dying patients in the ICU. The frequency of forgoing treatment and maintaining care is similar in patients who are in the ICU at the time of death and those who are not in the ICU at the time of death.

INTRODUCTION: The frequency of forgoing treatment and maintaining care in dying patients in the intensive care unit (ICU) is a controversial issue. Some authors have reported that the frequency of forgoing treatment and maintaining care is high in dying patients in the ICU, while others have reported that the frequency of forgoing treatment and maintaining care is low in dying patients in the ICU. The purpose of this study was to determine the frequency of forgoing treatment and maintaining care in dying patients in the ICU.

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capacity must be informed of reasonable treatment options and their possible outcomes. Patients who decide to forgo life-sustaining treatment should have these decisions honored. As a rule, a patient's considered decision should override contrary opinions of family or physicians, no matter how well-intentioned the opposing views may be.

When patients who cannot make decisions are concerned, the issues become more complicated. Before admission, Mr. McGee was fully capable of decision making, and conversations about his preferences for life support may have helped his family make decisions on his behalf. However, 60% to 70% of seriously ill patients, like Mr. McGee, are unable to speak for themselves when decisions to limit treatment are considered (3, 9). Although advance direc-

patients. The prognostic model developed for the Study to Understand Prognoses and Preferences for Outcomes and Risk of Treatments (SUPPORT) provides 2- and 6-month estimates of survival, but this information has been shown to have minimal impact on end-of-life care for patients with serious illnesses (20).

Given these limitations, would sophisticated ICU prognostic models have aided decision making for Mr. McGee? Possibly. However, most clinicians already incorporate some type of probabilistic reasoning when discussing prognosis with patients and families. Having objective estimates of survival may complement physician estimates and may help “plant the seed” in the minds of family members who have difficulty accepting that their loved one may die in the ICU. Because current prognostic models have considerable limitations, however, clinicians should use them only as an adjunct to the process of shared decision making (Table 1).

After discussions with Mrs. McGee, a do-not-resuscitate order is written and dialysis is stopped. The ICU attending physician suggests that the ventilator also be discontinued, and the family agrees. Before ventilator support is stopped, vaso-pressors and all medications except morphine and midazolam are withdrawn. The resident discontinues enteral feedings but restarts them an hour later at the attending's request.

Mr. McGee's care presented physicians and family with many decisions. Was the ICU the best place to care for him? Which interventions should be continued, and which should be stopped? Is “artificial nutrition” different from other life-sustaining treatment?

The practice of withdrawing treatment in ICUs has evolved during the past 20 years. When initial recommendations for discontinuing ventilator support were published in 1983, withdrawing ventilators was rare (21). Since then, withdrawing dialysis, ventilators, and other interventions has become much more common (22, 23). A study of 136 ICUs found that 74% of 5910 dying patients had some form of treatment withheld or withdrawn before death (2). However, interinstitutional variation was striking. Individual ICUs reported that anywhere from 21% to 96% of deaths were preceded by treatment limitation, and some ICUs reported no instances of withdrawing life support. This variation raises the question of whether these practice differences reflect physician or institutional values that ignore patient preferences.

Forgoing treatment may occur as a single, complete change in direction or may occur over time as specific treatments are gradually discontinued. In either case, procedures involved in forgoing treatment are inherently complex in ICUs, where several interventions are often in simultaneous use (24). It is important to note that in Mr. McGee's case, not all life-sustaining treatments were stopped simultaneously, enteral feedings were restarted at the attending's request, and inactivation of the pacemaker was not considered.

When considering the array of interventions that might be forgone, clinicians and surrogates should focus on clearly articulating the goals of care. Even when treatment is being withdrawn, goals vary considerably. Occasionally, the goal may be to remove a particular treatment perceived to be burdensome (for example, a ventilator that impairs communication and separates the patient from his or her family). Goals of short-term survival until important loved ones gather may justify continued ventilator support. Maintaining the ability to communicate may justify continuing vasopressors, whereas if the only goal is patient comfort, such treatment should be stopped. In general, interventions that do not contribute to achieving agreed-on goals, regardless of whether they are burdensome in their own right, should be discontinued. Throughout this process, explicit attention should be paid to measures that provide comfort to the dying patient and family. This includes assistance in completing important life tasks, such as family reconciliation, to the extent possible. Consultations with experts in palliative care can often help ICU staff provide comprehensive end-of-life care for patients and families.

D a

As in Mr. McGee's case, dialysis is often discontinued when other life-sustaining interventions are stopped. Unlike withdrawing a ventilator, however, stopping dialysis is unlikely to cause immediate death. In a small series of patients discontinuing chronic hemodialysis, death occurred after a median of 9.6 days (range, 2 to 34 days) (27). When dialysis is initiated for acute renal failure, patients occasionally recover renal function after dialysis is stopped, a possibility for which families should be prepared.

Several symptoms may accompany the cessation of dialysis. Dyspnea from volume overload can be controlled by restricting fluids, by administering opioids, and, rarely, by using ultrafiltration. Pruritus may be minimized by using emollients and antihistamines. Uremic nausea may be palliated with phenothiazines or butyrophenones, which also have sedating effects and may treat coexisting mental confusion (28).

A f c a. Feed

The clinical and ethical issues surrounding decisions to discontinue artificial nutrition have been discussed exten-

unexpectedly survive 1 or more days after ventilator withdrawal (39).

Dyspnea and anxiety should be anticipated when ventilator support is withdrawn by any method. Intravenous opioids and benzodiazepines are the drugs of choice to treat dyspnea and anxiety or agitation, respectively. Both should be immediately available and titrated to effect. These drugs may also be given before ventilator withdrawal to prevent anticipated symptoms from occurring. The ICU clinician's primary goal should be to ensure patient comfort and prevent suffering.

The amount of opioid or benzodiazepine necessary to relieve symptoms varies widely and depends on previous drug exposure (which induces tolerance), drug metabolism, and level of awareness. Typical doses of morphine given by continuous intravenous infusion (or repeated boluses) range from 10 to 30 mg/h. Occasionally, opioid-tolerant patients require doses of morphine at least one order of magnitude higher (for example, 500 to 1000 mg/h). Physicians and nurses should explicitly document that medications are being titrated to control symptoms. Care should focus on relieving the patient's discomfort regardless of the amount of medication needed. In Mr. McGee's case, ventilator support was decreased after inadequate doses of opioids and benzodiazepines. The increases in his respiratory rate that occurred after reduction of ventilator support should have been treated with additional doses of both agents, not by restoring full ventilator support.

Paralysis caused by neuromuscular blocking agents precludes the assessment of patient discomfort and the possibility of patients communicating with loved ones. For these reasons, these agents should be avoided when ventilators are being withdrawn. They should never be given

merely to make the patient "appear" comfortable. Before ventilator withdrawal, paralytic agents already in use should be stopped and their effects should be allowed to clear, or, if possible, they should be pharmacologically reversed (34, 40). If the effects of these agents persist beyond several hours (which is unusual), physicians and families should discuss the appropriateness of proceeding with ventilator withdrawal, given that patients in this situation remain at risk for unrecognized pain and discomfort (41).

E.ec ca d a c M a d Pace a e

After 30 minutes of terminal weaning, the family discusses what will happen to the pacemaker when Mr. McGee dies and how they will know he is dead if the pacemaker is still firing. Two hours later, Mr. McGee's son asks, "How low does the blood pressure have to go for it to be over?" After another hour, he says, "Enough is enough; it's time to stop." The resident is contacted and decreases the ventilator rate to 15 per minute.

Two hours later, Mr. McGee's oxygen saturation and blood pressure decrease precipitously. His blood pressure becomes unobtainable, although the monitor shows a paced rhythm at 80 beats/min. The ICU nurse pages the cardiology fellow, who disables the pacemaker. The monitor shows ventricular fibrillation, and Mr. McGee is pronounced dead.

Mr. McGee's family relied on his electrocardiographic monitor and vital signs to gauge the trajectory of his dying, even though such monitoring is relatively useless in assessing comfort or accurately predicting the time remaining

patient at a central station. This allows staff to determine when the heart's electrical activity ceases without distracting the family.

Although Mr. McGee had a pacemaker in place, the ICU team did not consider its inactivation when the decision was made to stop life-sustaining interventions. Temporary pacemakers are more likely to elicit such considerations, but a permanent pacemaker often goes unnoticed. Pacemakers, once implanted, rarely cause discomfort. However, if a patient wants to refuse all life-sustaining treatment, a permanent pacemaker or an implantable defibrillator should be inactivated (42, 43). The outcome of this action is unpredictable, however, because it is difficult to know what intrinsic rhythms will persist.

In Mr. McGee's case, no one anticipated that the pacemaker would interfere with the pronouncement of death. This exemplified the overall lack of detailed planning by the ICU attending physician, housestaff, and nurses in coordinating Mr. McGee's end-of-life care. At several points during ventilator withdrawal, the ICU resident was left alone to make treatment decisions without adequate knowledge or a clear plan of how to proceed. The resident's actions and inactions attest to the need for expert guidance from experienced clinicians. Attending physicians should not assume that residents instinctively know how to go about withdrawing treatment, much less that they know how to effectively palliate patient symptoms or address emotional or spiritual issues.

family and patient values at the end of life; and clinical outcomes beyond survival, including comfort and quality of dying, will help ICU clinicians better meet these challenges.

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