

Virtual Mentor

American Medical Association Journal of Ethics
June 2010, Volume 12, Number 6: 444-449.

CLINICAL CASES

Taking No for an Answer: Refusal of Life-Sustaining Treatment

Stephanie Cooper, MD, MS

Dr. Sachem, an emergency physician at a regional burns center, had kept the waiting room relatively empty for most of Memorial Day weekend, despite the recent warm weather. At 3:00 AM on Monday, a patch came over the radio. Injured firefighters from a two-alarm house fire were being brought in by ambulance. Five minutes later, the trauma bay was enveloped with the acidic smell of soot and burnt flesh.

A badly burned 41-year-old fireman named Worther complained only of leg pain. “Hey Doc! You gotta fix my leg. We were on the first story trying to get back to the master bedroom when I realized that the fire had started in the cellar. Before I knew it, I was trapped downstairs under a beam.” The medic, who was at the blaze, reported that Mr. Worther was in the flames for 3 minutes before he was extracted. The first responder’s look at Dr. Sachem told her that there was something else that couldn’t be spoken.

The medics had removed much of Mr. Worther’s scorched clothing en route; when the trauma team opened the blankets, skin peeled off with the cloth and much of his body had a white sheen to it. The fireman’s right leg had a compound fracture of the femur and was scorched black. His left hand, shoulders and face were spared, but his mouth and beard were full of soot. Dr. Sachem calculated that full-thickness burns covered 85 percent of Mr. Worther’s body and suspected significant smoke inhalation. She recalled a tragic case in her residency when the ICU team couldn’t keep up with a badly burned patient’s fluid losses and the patient died after 3 weeks on a ventilator. This was what the medic had been saying with his eyes. But recent efforts at her burn center suggested the patient might have a 10 percent chance of survival.

After she told him of the burns’ extent, the firefighter asked earnestly, “Am I going to make it, Doc?” Dr. Sachem responded, “We’re going to put in a central line to give you fluids and will get ready to intubate you because you’ll soon have trouble breathing on your own.” As she set up her equipment, the patient asked his colleagues to leave the room. He looked Dr. Sachem in the eye and clearly told her, “I’ve seen my share of burn deaths and I know where this is heading. Please let me die. Just give me something so I don’t feel anything, but don’t let me live.”

Commentary

One of the greatest dilemmas for emergency physicians occurs when a patient refuses medical treatment that is necessary to sustain life and health. When patients in need explicitly refuse life-sustaining emergency treatment, the physician must choose between the undesirable options of forgoing beneficial treatment and forcing treatment on a competent but unwilling patient [1], both of which have potential ethical and legal consequences. The “emergency privilege” does not permit physicians to treat competent patients with emergency conditions who refuse treatment; but how does one assess an injured patient’s decision-making capacity?

In the case presented above, Mr. Worther has sustained full-thickness burns over 85 percent of his total body surface, inhalational injury, and a fractured femur. Most physicians would argue that these injuries are not compatible with life. Yet in the emergency setting, we can certainly prolong his life, thwart imminent death, and increase the likelihood of survival by initiating immediate treatment with IV fluids and ventilatory support. This will at least allow time for full evaluation and, perhaps, a more accurate prognosis. But Mr. Worther is refusing this life-sustaining treatment. Based on these facts, we need to determine whether or not he has decision-making capacity and, if so, whether he understands the consequences of treatment refusal.

Decision-making capacity (DMC) exists along a continuum, referring to the ability of a patient to make a specific decision at a specific time; it is not a global determination. “Medical decision making capacity is present when the patient is able to understand information about the medical condition and its consequences, to reason and deliberate about the various choices, to make a choice consistent with his or her values and goals, to communicate this choice to the physician, and to maintain this choice consistently over time” [2].

The right of competent, non-terminally ill people to refuse lifesaving medical treatment was widely publicized in the case of Dax Cowart, a 25-year-old who was severely burned. Mr. Cowart, who is now a lawyer, argues that, as a person with intact decision-making capacity, he had the right to refuse treatment and die and that this right was violated [3]. Two psychologists found Cowart competent to refuse care on the grounds of his excruciating pain and his view that his future would be incompatible with his desired quality of life. His physicians, who argued that he lacked decision-making capacity and thus could not reject treatment, overrode Cowart’s refusal of care. In other legal cases, lifesaving treatment against a competent patient’s wishes has resulted in suits for battery, medical negligence, and lack of informed consent [2].

Determining capacity to consent to or refuse treatment is a clinical judgment based on the patient’s cognitive and physical functioning and the complexity, risks, and possible repercussions of the medical treatment at hand [1]. It is an essential skill for emergency physicians, who frequently must delicately and accurately walk the tightrope between medical urgency and ethical imperative. Assessing decision-making capacity is central to providing medical care that respects patient autonomy,

since patients' consent to or refusal of medical treatment is not valid unless they are capable of making medical decisions [1].

Informed consent and informed refusal allow competent patients to choose among treatments in accordance with their values, goals, and priorities for their future. When patients refuse recommended life-sustaining medical treatment, the duty rests with the physician to discern whether the patient has the decision-making capacity to reject treatment. Refusal of care in the ED setting creates tension between beneficence and patient autonomy, with the critical determination of decision-making capacity in the balance.

There are multiple models that can be utilized to evaluate DMC. One model encourages physicians to assess the following: absence of any gross deficits in cognition, patient judgment, understanding, ability to choose between different options, ability to express a choice, and stability of the choice over time [4]. Another model, the MacArthur Competence Assessment Tool for Treatment, is a structured interview tailored to the patient's specific situation, which takes 20 minutes to administer and score [5]. Currently, there are no formal practical guidelines issued by professional societies for assessing a patient's DMC. This is most likely due to the uniqueness of each patient's scenario and the fact that DMC must be evaluated on a case-by-case basis.

In general, if a patient with decision-making capacity refuses the recommended medical treatment, his or her refusal must be honored and accepted [7]. If the patient refuses a lifesaving treatment, however, should the decision be held to a different standard?

In a "sliding scale" model of decision-making capacity, as the risks and consequences increase, patients may need to demonstrate higher levels of decisional capacity than under less critical circumstances [6]. This model is calibrated to reflect the risks associated with the patient's choice by increasing the stringency of the capacity standard required [7]. To use it, physicians must navigate between respecting patient autonomy and protecting patients from the possibly mortal consequences of a bad decision [2]. In the end, what must be proven is that a patient made an autonomous decision based on maximizing self-interest as he or she defines it, even though the choice was not the expected or physician-recommended choice for the majority of patients facing the same decision [8].

Decision-making capacity can be altered or obscured by pathophysiological conditions, such as acute physical or mental illness, traumatic brain injury, severe pain, pain medications, substance use (withdrawal or overdose), and emotional factors, including stress, denial, and suicidal ideation. Certainly, a comatose patient, a severely demented patient, or an intubated, head-injured patient lacks decisional capacity. Under the "emergency exception," immediate intervention can proceed without informed consent in order to prevent death or serious disability. The

emergency exception is based on the presumption that a reasonable person would consent to treatment to preserve life and health if he or she were able.

Conversely, the patient who is alert, communicative, and comprehends the situation has the ability to direct his or her health care. The grey areas lie in between. In actuality, decision-making capacity is more often questioned when the patient refuses recommended medical treatment [7]. While the factors mentioned above may limit the patient's decisional capacity, it is essential that the emergency physician not equate presence of an impairing condition with the lack of decision-making capacity [9]. Similarly, disagreement with the physician's recommendation is not grounds for determining that the patient lacks decision-making capacity.

In the emergency setting, there are limitations on determining DMC. When faced with medical emergencies requiring urgent action and decision making, the emergency practitioner does not have the luxury of time to consult psychiatric professionals, an ethics committee, or hospital legal counsel. Truly emergent situations are by definition time-limited, and the practitioner must assess DMC as best as he or she can. The culture of emergency medicine is to preserve life at all costs. In the immediacy of illness and injury, survivability and outcome cannot be predicted. Consequently, emergency physicians typically "err on the side of life" [10].

But how does the medical response change if treatment of the life-threatening illness might be futile? As a firefighter who has witnessed other burn victims' injuries and deaths, Mr. Worther may understand better than most the significance of his injuries. Currently he is coherent and able to state the reasons for his refusal of care. There is no evidence that his sensorium is clouded by pain medications, pain (because the burns are full-thickness, Mr. Worther is insensate), or other pathophysiologic process. Additionally, he has dismissed his coworkers from the room, so it does not appear that he is under any emotional or psychological duress. In other words, Mr. Worther appears to be a competent patient acting volitionally, expressing a choice that is consistent with his values and wishes. Should Dr. Sachem honor Mr. Worther's right to refuse treatment?

Honoring the severely burned firefighter's request to withhold treatment allows him to die from his underlying disease and injury. From a clinical perspective, one could argue that providing medical treatment in this case simply prolongs death rather than preserves life. Mr. Worther is seeking pain medication only, not prescription of a lethal medication. By honoring his request to withhold life-sustaining treatment, we are honoring the autonomy of a patient with decisional capacity who understands the risks of treatment refusal. Providing some patients a dignified death may be just as critical as saving the lives of others [11].

References

1. Moskop JC. Informed consent in the emergency department. *Emerg Med Clin North Am.* 1999;17(2):327-340, ix-x.
2. Derse AR. What part of “no” don’t you understand? Patient refusal of recommended treatment in the emergency department. *Mt Sinai J Med.* 2005;72(4):221-227.
3. Confronting death: who chooses, who controls? A dialogue between Dax Cowart and Robert Burt. *Hastings Cent Rep.* 1998;28(1):14-24.
4. Thewes J, FitzGerald D, Sulmasy DP. Informed consent in emergency medicine: ethics under fire. *Emerg Med Clin North Am.* 1996;14(1):245-254.
5. Appelbaum PS. Assessment of patients’ competence to consent to treatment. *N Engl J Med.* 2007;357(18):1834.
6. Withers E, Sklar DP, Crandall CS. Impairment and severity: how ED physicians decide to override an impaired patient’s refusal. *Am J Emerg Med.* 2008;26(7):803-807.
7. Miller SS, Marin DB. Assessing capacity. *Emerg Med Clin North Am.* 2000;18(2):233-242, viii.
8. Magauran BG Jr. Risk management for the emergency physician: competency and decision-making capacity, informed consent, and refusal of care against medical advice. *Emerg Med Clin North Am.* 2009;27(4):605-614, viii.
9. Moskop JC. Informed consent and refusal of treatment: challenges for emergency physicians. *Emerg Med Clin North Am.* 2006;24(3):605-618.
10. Derse AR. Ethics and the law in emergency medicine. *Emerg Med Clin N Am.* 2006;24(3):547-555.
11. Keyes LE, English DK. Cultivating conscience: learning to make end-of-life decisions in the emergency department. *Ann Emerg Med.* 1999;33(4):464-468.

Further Reading

Miller FG, Fins JJ, Snyder L. Assisted suicide compared with refusal of treatment: a valid distinction? University of Pennsylvania Center for Bioethics Assisted Suicide Consensus Panel. *Ann Intern Med.* 2000;132(6):470-475.

Larkin GL, Marco CA, Abbott JT. Emergency determination of decision-making capacity: balancing autonomy and beneficence in the emergency department. *Acad Emerg Med.* 2001;8(3):282-284.

Palmer RB, Iserson KV. The critical patient who refuses treatment: an ethical dilemma. *J Emerg Med.* 1997;15(5):729-733.

Pope TM. Legal briefing: medical futility and assisted suicide. *J Clin Ethics.* 2009;20(3):274-286.

Stephanie Cooper, MD, MS, is an emergency medicine physician at Harborview Medical Center in Seattle and an assistant professor at the University of Washington

School of Medicine. Her academic interests are bioethics, humanities, and narrative medicine. She teaches Ethics in the ER, a course that introduces medical students to critical ethical concepts in the context of emergency medicine.

Related in VM

[Informed Refusal in the Emergency Department: Is It Really Informed?](#) August 2008

The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental.

The viewpoints expressed on this site are those of the authors and do not necessarily reflect the views and policies of the AMA.

Copyright 2010 American Medical Association. All rights reserved.