

## MEDICINE AND SOCIETY

## Chronic Critical Illness

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Early in my intern year, I admitted an 80-year-old man with pneumonia to the intensive care unit (ICU). He had hypotension and was struggling to breathe, and my senior resident and I told his family that it was touch and go. Their response: Do everything. He had repaired cars for a living, and he was a tough guy, a fighter.

Ten days later, his condition had stabilized, but he was delirious and unable to breathe on his own. We told his family that if we were to continue, he'd need a tracheotomy and feeding tube. They agreed without question. We had saved his life. A bed at a long-term acute care (LTAC) hospital opened up 3 weeks after he was admitted, and I rushed to get the last-minute transfer ready. I never saw him again.

His is not a unique story. But it stands out in my memory because this man was one of the first patients I helped carry from the brink of death to the brink of life, to join an estimated 100,000 U.S. patients with chronic critical illness at any one time. And it troubles me still, because the narrative remains unfinished. Did he ever wake up, or breathe without the ventilator? Did he go home? Did he even live, and if not, where did he die?

The data are discouraging. "Chronic critical illness" is a nebulous term for the condition of the 5 to 10% of patients who survive a catastrophic illness or surgical procedure but are left with a prolonged (by one definition, longer than 21 days) need for mechanical ventilation. These patients tend to have recurrent infections, organ dysfunction, profound weakness, and delirium. At least half are dead within 1 year. Among those who survive, readmission rates are high, most remain institutionalized, and less than 12% are at home and functionally independent 1 year after their acute illness. The cost to the health care system is astronomical — more than \$20 billion annually.<sup>1</sup>

Nevertheless, in my experience, physicians-

in-training are largely unaware of this burden of disease. By its very nature, critical care is not a field with follow-up. Only recently has the specialty focused in on the cognitive deficits, depression, and post-traumatic stress that follow critical care. In addition, the expansion of LTAC hospitals during the past two decades — described to me by one physician as "where Lazarus meets Darwin" — quite literally takes chronic critical illness out of view of the physicians who care for these patients during the acute phase of their illness. As a result, I believe, we do our patients a disservice despite our best efforts. "We — intensive care clinicians — have created chronic critical illness, and that makes it especially painful to see. The model that provides ongoing critical care for patients in LTAC [hospitals] and nursing homes shields those patients from our view inside the ICU," says Judith Nelson, a palliative care and critical care specialist at New York City's Mount Sinai Hospital who has conducted seminal research in this population. "This is a disease. It's sometimes or even often worse than some cancers in terms of its mortality and effect on quality of life. People know what cancer means. They've heard of it. But they've not heard of this."

Indeed, numerous studies reveal that we are, quite simply, bad at talking to families about prolonged illness. One study showed that patients receiving mechanical ventilation for prolonged periods and their families frequently misinterpreted the need for a tracheotomy as a move toward recovery, rather than a herald of protracted debility.<sup>2</sup> A survey of patients or surrogate decision makers for 100 chronically critically ill patients who had recently undergone tracheotomy revealed that the majority had made key decisions without any information about expected 1-year survival, functional status, cognitive status, or alternatives to continuing mechanical ventilation.<sup>3</sup> In another study, less than half

of patients with an ICU admission lasting longer than 2 weeks — or their surrogates — had discussed their prognosis with a physician.<sup>4</sup>

Perhaps one reason for our failure here is that we don't have a strong grasp of what chronic critical illness is. A recent study asked surrogates and physicians about their expectations at the time of a patient's tracheotomy. Surrogate-physician pairs had highly discordant views of expected outcomes, and the outcomes were ultimately worse than what either physicians or surrogates expected.<sup>5</sup>

At LTAC hospitals, the ramifications of our communication failures are felt daily. Julie Zuis is the nurse manager at Spaulding Hospital for Continuing Medical Care in Cambridge, Massachusetts, where she has worked for 30 years. Families often arrive at Spaulding with substantial misconceptions about what a patient's transfer to an LTAC hospital means. Some are surprised to find that ICU-level monitoring no longer occurs; others are frustrated that no one is forcing their loved one onto a treadmill 3 hours a day. Frequently, Zuis notes, families will reverse a do-not-resuscitate order on arrival, with the expectation that "we are going to get people back to where they were, and maybe better."

These expectations are worlds away from reality. How can physicians-in-training — who are often the ones who hold these conversations in the ICU — begin to bridge that gap? During my residency, I had only a vague notion of an LTAC hospital as modern-day purgatory, and I'd never even heard the term "chronic critical illness," despite taking care of many patients who had it. One step could be incorporating chronic critical illness into medical school curricula alongside the metabolic syndrome and congestive heart failure. Formal trainee education could help us recognize and understand the course of chronic critical illness and perhaps even give us tools to offer our patients and their surrogates clear, accurate information when it comes to key decision-making moments. Involving a new generation of physicians could also spark interest and advance a research agenda in the field, Nelson suggests. For instance, the biology underlying these patients' neuroendocrine abnormalities, muscle breakdown, and increased susceptibility to infection remains open for study.

House officers increasingly receive formal

training before leading conversations about the goals of a patient's care. Discussing the pros, cons, and long-term sequelae of a tracheotomy and of subsequent transfer to an LTAC hospital is another area in which we could benefit from further formalized training, with observation and feedback. An ongoing trial, sponsored by the National Institutes of Health, of protocolized, multidisciplinary support meetings and informational aids for this population (ClinicalTrials.gov number, NCT01230099) could ultimately provide us with proven tools for conducting these conversations well. Furthermore, some recent data suggest that we might be able to improve our prognostication for these patients. One scoring system uses four characteristics of patients in acute care settings — an age of more than 50 years, a low platelet count, and the need for vasopressors and for dialysis — to delineate a subgroup of patients who are at the highest risk of death.<sup>6</sup> Integrating a model like this one into clinical practice could enable us to have clearer conversations that lay out likely outcomes and alternatives, including withdrawal of further interventions.

For trainees at hospitals that are near LTAC hospitals, a brief rotation at such a facility could be coupled with required time in the ICU. Although there are currently more than 400 LTAC hospitals in the United States, they're not evenly distributed geographically; in regions lacking such facilities, a rotation through an in-hospital respiratory care unit could serve a similar purpose. The primary goal would be to offer firsthand experience to inform decision making in the acute care arena. In addition, involving house officers in LTAC hospitals could encourage an academic look at best practices and outcomes in an arena where such perspective has historically been lacking.<sup>7</sup>

It's been 5 years, but I still think about my internship patient from time to time. There have been so many others like him. And when I consider their stories, I find that my pride in medicine is tempered slightly by regret about missed opportunities for communication and uncertain follow-up. I can't be sure what effect, if any, integrating these patients into medical school and residency curricula would have on a problem that is so deeply entrenched in our health care system. But we owe it to our patients to try. Fac-

ing a future in which the numbers of chronically critically ill patients are expected to increase, we can't continue to look away.

Disclosure forms provided by the author are available with the full text of this article at NEJM.org.

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