How COVID-19 Made It Even Tougher to Know ICU Patients as Individuals

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H is desire to save lives led E. Wesley Ely, MD, MPH, to a career in pulmonology and critical care. He spent 15 years as an intensivist before realizing that the life-saving measures he and his colleagues used, which left intensive care unit (ICU) patients tethered to technology, sometimes unconscious in their beds, often irrevocably changed those lives for the worse.

It didn’t have to be that way. Ely, a professor of medicine at the Vanderbilt University School of Medicine, helped spearhead the Society of Critical Care Medicine’s ICU Liberation, an initiative aimed at reducing the long-term and short-term consequences of ICU stays, which even before the COVID-19 pandemic numbered in the millions each year in the US.

Ely and others soon recognized that family members played a key role in improving ICU care because they could serve as the voice of patients unable to speak for themselves. But the COVID-19 pandemic brought new challenges when hospitals banned visitors, and besieged ICU physicians and nurses didn’t have enough time to call family members for help in filling in the blanks about patients.

Ely spoke recently with JAMA about how the COVID-19 pandemic set back progress that had been made in critical care medicine and the lessons that have been learned. The following is an edited version of that conversation.

JAMA: Why did you become interested in how ICU patients fared after they left the hospital?

DR ELY: I had a patient early on for whom I thought we had done such a great job. She came back to see me after a long ventilator stay. I was expecting her to walk in and thank me for saving her life. I was expecting her to walk in and thank me for saving her life. Instead, she was wheelied in by her mother and unable to communicate well. She had had her life completely dismantled by this critical illness, and she really became the index patient for me of what we now know as post-intensive care syndrome, or PICS. I’d never been taught anything about how the ICU can ruin somebody’s life, and that’s kind of gotten me onto a long process of working through my own guilt and shame for what I had done to her and avoiding doing that to people in the future.

JAMA: What are the components of A2F?

DR ELY: A is analgesia, and we just want to make sure that really takes care of people’s pain and suffering. B stands for spontaneous tests of their ability to be awake and to breathe. We can reduce time in the ICU and time on the ventilator just by turning off sedation and the breathing machine and allowing the patient to do the work. C is choice of drug. We try and avoid drugs like benzodiazepines, which cause a lot of delirium. D is delirium, and we monitor patients for it because when somebody can’t pay attention and can’t think well it’s very depersonalizing for them. It’s almost a form of injustice toward the patient because they can’t know what’s going on and all the power then resides in the medical team. E is early mobility, and it reminds us to wake them up and get them out of bed. As soon as they start getting out of bed their brain starts working better and their muscle and nerve disease abates and doesn’t progress like it would if they were languishing in bed. And then the F is family, and family we have found to be a critical part of the healing process for the patients. All during COVID the family was sequestered away from the patient. I think that isolation and loneliness probably contributed to a lot of deaths. We’ll never know the full amount of harm and the holes in the hearts of the patients unable to be with their loved ones.

JAMA: Hindsight is 20/20, but do you think hospitals went overboard last year as far as keeping friends and family away from ICU patients’ bedsides?

DR ELY: We all did the best we could with the light we had at the time, which was a dim light. We were scared, we had an infection we didn’t understand yet, and we also had a shortage of PPE [personal protective equipment]. As soon as there was no longer a shortage of PPE and we knew that it worked, then we were overdoing it. We kept the isolation going. I’ve really kind of made...
myself a nuisance to hospital administrators by opposing these policies. Rana Awadish, MD, and I wrote a Washington Post op-ed early on in the first summer of the pandemic arguing against any further isolation and loneliness for the patients. And we published a study of 2100 COVID ICU patients in which only 7% had any interactions with their family and loved ones, even via Zoom, toward the beginning of the pandemic. I think that’s a horrible thing to do to people. I think it is unjust, and I think it accelerates disease and death.

**JAMA:** Vanderbilt was one of the first hospitals to reopen visitation during the pandemic. Did your work spur that move?

**DR ELY:** I do not take credit for that. Our excellent ICU leadership and lots of other colleagues were quick to point out that we need to get patients and their families at the bedside. I was taking care of a lupus patient early on who was desperate to see her mother, and we were able to get the mother and father in at the bedside. She was not a COVID patient, but it was during the lockdowns, and that was the first patient to my knowledge who had family at the bedside in the ICU. We did have to argue for that. Everybody started seeing the benefit, and then it was months later when we started allowing patients to be with their families again.

**JAMA:** You founded and codirect the Critical Illness, Brain Dysfunction, and Survivorship (CIBS) Center at Vanderbilt. What is the center’s purpose?

**DR ELY:** The CIBS Center is a group of more than 100 researchers at Vanderbilt and the VA [Veterans Affairs] hospital. We have about $35 million of NIH [National Institutes of Health] and VA funding and lots of other types of funding to conduct state-of-the-art, cutting-edge research to improve the care of people in the ICU and the long-term outcomes of people trying to recover after surviving the ICU. And we study the brain and the ramifications of delirium leading to dementia during critical illness. We study mental health issues that COVID patients are suffering from so dramatically as a form of long COVID, and we also study the physical abnormalities that are affecting patients, such as ongoing breathing, heart, and muscle and nerve problems. The CIBS Center is a way to help humanize medicine and make sure that we see that person in the patient, rather than just critical illness and technology.

**JAMA:** It’s also an opportunity for patients to get together, right?

**DR ELY:** We have multiple support groups every week that bring together ICU survivors, COVID survivors, spouses. We are getting back to in-person, but right now they’re all conducted via Zoom. This is a time for people to share with one another, a time to help them in their recovery, and there are a lot of tears. There’s a lot of joy too, though, and a lot of laughter, and it really functions a lot like other types of recovery groups.

**JAMA:** How has COVID-19 changed the ICU playbook?

**DR ELY:** COVID-19 took us backwards about 20 years initially. Back in the ’90s, we kept people in a deep coma, sedated and immobilized for days and days on end, and we just didn’t know how much damage this was causing to their mind, body, and spirit. And then around 2000 we started understanding the role of delirium. We came up with tools like the CAM ICU, the confusion assessment method for the ICU, and then started using those tools to conduct randomized controlled trials, which have been proven to improve survival and reduce the long-term suffering by getting rid of the coma and liberating patients from this ICU care sooner. We made great progress in 2015 up to 2018 and we were actually seeing 30%, 40% drops in delirium. COVID completely erased all that progress. There were times when I was in the ICU and I honestly felt like it was the 1990s. Patients were on long benzodiazepine drips and in comas. They were not getting mobilized and didn’t have family around.

**JAMA:** Are patients with COVID more likely to experience delirium than other ICU patients? And, if so, why?

**DR ELY:** They absolutely are more likely to experience delirium. There are numerous reasons that may happen. The virus itself can invade the brain, although that’s not a major reason for the delirium. Patients with COVID get a lot of lung destruction and have drops in their oxygen levels, and the brain needs oxygen to think clearly. We have a lot of blood clotting in COVID, so the neurons don’t get food and oxygen. But then there are the iatrogenic parts of the delirium, the parts that we cause. We give them drugs, like steroids, like dexamethasone, and those are very deliriogetic. We immobilize the patients and we take the family away. COVID has caused us to have a reawakening of the importance of liberating patients from ourselves and from the things that we impose very paternalistically on them. How is it that I can best care for this person today? And that’s got to start with looking them in the eyes, seeing who they are, letting them wake up.

**JAMA:** Does the appearance of heavily sedated ICU patients unduly influence decisions about their care, both by their loved ones and their physicians?

**DR ELY:** I know from personal experience that when someone is deeply sedated it does affect how they’re cared for. When I see somebody and they don’t interact with me,
I can allow myself to distance and not treat them as a real person. I don’t get to think of who they are, ask them questions. It’s really a travesty in the way we care for these ICU patients, and I didn’t even realize it for my first 15 years as an intensivist.

**JAMA:** What a challenge it must have been during the pandemic when family members and friends could not even come into the hospital. How were intensive care physicians supposed to get to know anything about their unconscious patients?

**DR ELY:** Actually, we didn’t. We could get on the phone with their families and ask them some questions, but we were so busy just dealing with shock and ventilator adjustments and trying to figure out which drugs to use or which drugs to avoid. Those phone calls basically became updates that were very short. We called one woman and told her 4 or 5 minutes’ worth of information about her husband and she said, “Well, that’s it?” So we started adapting our phone conversations to become 30 minutes long. That’s hard when you have 25, 30, or even more COVID patients. Where do you find the personnel to spend that sort of time on the phone with them? That didn’t happen enough. We didn’t know about our patients.

**JAMA:** In your new book, *Every Deep-Drawn Breath*, you write about viewing ICU care from the other side of the bed after your daughter fell from a high diving board. How has that experience informed your work?

**DR ELY:** When our young daughter fell off that high diving board, she had a major skull fracture and was unconscious, seizing. It was a gut-wrenching experience. She was in the neuro ICU, and I felt an immense amount of guilt and shame for ever letting her up on that board. But what happened to me as a physician was something altogether different. We are taught to examine the patient from the right side of the bed, and the family generally sits on the left side of the bed. All of a sudden, I found myself on the left side of the bed, waiting for neurosurgeons to walk in the room. They were giving me a short script, and I realized this was a form of testimonial injustice, where they held all the power. I didn’t feel included in the decision-making, and I vowed that I would not put patients and families through that experience and would dig deep to find the time to sit down and talk to them and find out what mattered to them and hear what they were afraid of. I don’t pretend to do a perfect job of this, but that experience with my daughter definitely catalyzed that change in me as a physician. •

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