Flashbacks plague former ICU patients

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Filmmaker and professor Nancy Andrews suffered symptoms of PTSD after a lengthy hospitalization in Boston.

In 2003, Lygia Dunsworth underwent gallbladder surgery at a Texas hospital. The routine procedure became complicated when she developed recurrent bacterial blood infections, which then led to the insertion of a breathing tube and multiple abdominal surgeries. She developed pneumonia and spent weeks heavily sedated, in and out of consciousness. She left the hospital five months later.

As a nurse, Dunsworth, 45, knew she would require intensive physical rehabilitation. But she wasn't prepared for the flashbacks. She was drowning, poisoned by nurses, crawling on the floor of a walk-in

freezer full of amputated limbs. The images came to her unbidden, memories of events she had never experienced.

Worried that she would be labeled “crazy,” Dunsworth told no one. Eventually, she returned to work. The flashbacks came less frequently, but never disappeared completely.

Last month — nearly a decade after her stay in the intensive care unit — Dunsworth happened upon a study published by investigators from Johns Hopkins University in the journal Psychological Medicine. It described symptoms of post-traumatic stress disorder (PTSD) in survivors of critical care.

“This is my story,” Dunsworth thought.

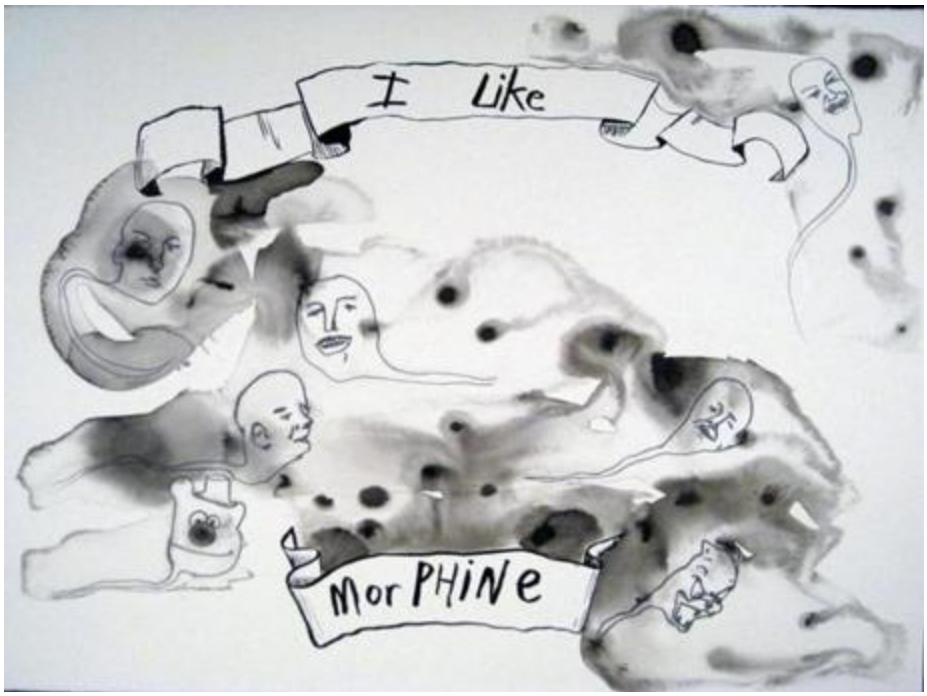
With new drugs and technologies at their disposal, physicians are becoming better and better at saving lives.

Recently, however, researchers have described a troubling phenomenon: Not only do survivors of the ICU suffer high rates of depression and cognitive dysfunction, but also as many as one in three who are sick enough to require a breathing tube also develop symptoms of post-traumatic stress disorder. While it is more likely to occur in patients with preexisting depression, it can also appear in those without any psychiatric history.

A soldier suffering from PTSD may experience flashbacks of tanks and bombs, terrifying moments of their waking life. In contrast, an ICU survivor may suffer flashbacks of delirium-induced nightmares they had in the hospital, rather than real events. While this is not PTSD as traditionally defined, physicians argue that it is no less debilitating.

“You tend to believe you’re the only one,” says Nancy Andrews, a Maine filmmaker and college professor who suffered symptoms of post-traumatic stress disorder after a lengthy hospitalization in Boston for a life-threatening tear in the wall of the aorta. “You wonder what is wrong with you? You made it out of the hospital, why can’t you get it together?”

The idea that delirious hallucinations could lead to post-traumatic stress disorder is new even for physicians who work in the ICU daily.



Nancy Andrews has created a sequence of drawings and a film fueled by memories of delirium.

Historically, patients were heavily sedated throughout their critical care stay with the dual goals of pain control and amnesia, to prevent patients from having memories of painful breathing tubes, or urinary catheters.

However, research in the past decade has led to a paradigm shift. In 2000, the New England Journal of Medicine published data showing that interrupting sedation daily in intubated patients shortened the amount of time on a breathing tube, and got patients out of the ICU faster. Daily interruptions of sedation, termed "sedation holidays," became standard.

Fast forward a few years, and physicians now know that delirium itself — the waxing and waning alertness that often afflicts the critically ill who have been sedated — is associated with higher mortality, longer stays in the ICU, and higher costs. These findings have ushered in new practice guidelines, medication changes, and scoring systems to measure patients' level of delirium.

Against this backdrop comes the somewhat controversial suggestion that patients may leave the ICU to find themselves psychologically devastated. When Christina Jones, a nurse consultant in the United Kingdom, looked to start a post-ICU support group in the late 1990s, she was surprised that the former patients refused to return to the hospital. They met in a local pub instead. Listening to the patients' stories, Jones said she came to understand why.

"I started to see this pattern of people with flashbacks and nightmares," said Jones, who pursued a doctorate to study this population more rigorously. "They had very little factual memory, but also had these hallucinations, paranoid delusions of nightmares and alien abductions and nurses trying to kill them. That seemed to be the precipitant for PTSD for a portion of the patients — they couldn't reject these memories."

Researchers in the United States, too, were making similar observations. James Jackson, a Vanderbilt University psychologist and assistant professor of medicine who specializes in survivors of critical illness, recalls interviewing critical care survivors for the group's studies of long-term outcomes. He

had previously worked with combat veterans and noted a similar constellation of flashbacks, avoidance, and high levels of anxiety in the ICU survivors. However, there was a key difference.

“If you interview these people, you realize a lot of what freaked them out the most are things that never did happen,” said Dr. O. Joseph Bienvenu, a psychiatrist at Johns Hopkins who co-authored the recent paper describing PTSD in one-in-three ICU survivors. Bienvenu notes that while some patients find themselves haunted by factual memories, more of them report being tortured by sadistic fun-house mirror distortions of actual experiences. For instance, he will often hear stories about flashbacks of sexual abuse, likely related to the necessary, but intrusive, placement of a urinary catheter.

“Too often we give people so much sedation that they can’t remember anything and we are doing that in order to protect them. But now we know that the total absence of memory is a driver of PTSD,” said Dr. E. Wesley Ely, a Vanderbilt professor of critical care and a VA researcher.

Already, practitioners are moving away from the medications most likely to cause delirium. Given the association between delirium and flashbacks, studies suggest these same medications are more likely to be associated with patients’ developing PTSD. But the sickest in the ICU will continue to require deep sedation. This has led researchers to question: If the absence of memory is at fault, would providing patients with a record of their hospital stay help?

That rationale led to the creation of the ICU diary, a day-to-day record of a patient’s ICU stay, in simple language and with photographs. Jones and her colleagues in the United Kingdom have recently published data showing that patients who are given diaries of their ICU stay exhibit significantly lower rates of PTSD than their counterparts without such a record.

In the United States, ICU diaries are not widespread. Jones contributes to a website that serves as a worldwide network for health care workers interested in starting an ICU diary program. There are just a handful of hospitals that have joined, but momentum is growing. In Boston, nurses at Massachusetts General Hospital have started creating diaries for ICU patients who are expected to have a protracted course of sedation while attached to a breathing tube.

“It has very quickly become clear that patients are desperate to fill the gaps in their memories,” Jones said.

She notes that even patients who seem to be doing well might be hiding delusional flashbacks.

“Often, they are sort of vaguely embarrassed, they shouldn’t be saying the nurses tried to kill them, they are grateful to be alive,” Jones said. “And they don’t want you to think they’re going mad.”

Andrews calls herself “the luckiest unlucky person.” In her memories, the ICU was a horror show of people trying to kill her, ants crawling on faces, finding herself “on a raft, in a space-pod . . . in the Arctic, in the desert . . . each with its own terrible narrative.” When she was finally sent home from rehab, her primary care doctor recognized that her tearfulness and avoidance (she would panic and weep at the sound of a helicopter, having been airlifted from Maine to Boston) might be symptoms of PTSD. Andrews sought psychiatric care and eventually found a treatment regimen that helped her, slowly, ease back into her life.

Her experience isn’t the norm. Ely and the team at Vanderbilt recently started a follow-up clinic for ICU patients. But there are few such clinics in the United States. As a result, most patients return to their primary care physicians, who frequently don’t know to probe into the nature of their ICU

memories. And if no one asks, patients might go years before they admit their experience and seek help — if ever.

Andrews is using her skill as a filmmaker and visual artist to reach others with shared experiences. She set up a website that describes her memories, and offers readers links to further information. She has created a sequence of black-and-white drawings and an avant-garde film fueled by memories of delirium.

She can't advise the ICU team on how to do its job to save the critically ill, Andrews notes, but she can help fill the "what now" void that faces patients when they return home.

"So often, we're lulled into thinking that we've done our job when these people are wheeled out of the ICU," said Jackson, the Vanderbilt psychologist. "But we need to recognize that in some cases, when people survive the ICU, their journey is only beginning."

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