“Taking critically ill patients as autonomous agents—part of the ‘decision-making team’—fails to respect the precarious position such patients find themselves in.”
In 1998, I spent almost a month in an ICU with invasive group A streptococcus infection and multiple organ failure, including severe acute respiratory distress syndrome (ARDS).

When I awoke in the middle of the night with screaming pain in all my joints, my general practitioner surmised that I might have some kind of arthritis. An appointment was made with a rheumatologist in a teaching hospital. As I waited, I was in rapid decline. The rheumatologist took one look at me, put a blood pressure cuff around my arm, declared that I had very little blood pressure, and called an ambulance to take me to the emergency room.

They had a very difficult time getting a line in; my lungs failed; and I descended quickly into multiple organ failure. Twice my husband was told that I wouldn’t make it through the night. I owe everything to those critical care physicians who worked night and day to secure my survival.

The critically ill undergo much distress. Some of that distress is physical. But some of that distress is psychological and emotional. We know, for instance, that ICU delirium is rampant in the critically ill patient population.

I recently had an interesting view on one of my worst delusions. I was able to read volume one of my thick file that included a detailed account of my ICU stay and one of the most interesting sections concerned my trying to effect what is quite gloriously understated in the literature as an “unplanned extubation.”

The log makes it clear that things are going very badly: I’m in a psychotic state; my vital signs are plunging; my husband, who has for the first time in weeks been able to go home, is called; my brother is ‘agitated’; and the writing is getting progressively more urgent and panicky. An anti-psychotic is dumped into me, which only makes things worse.
worse. Then in capital letters, the following sentence appears: “PATIENT IS TOLD THAT IF SHE RIPS THE TUBE OUT OF HER THROAT, SHE WILL DIE. PATIENT CEASES ATTEMPT TO SELF-EXTUBATE.”

Once things had become less precarious, I was very anxious to get off the ventilator and out of the ICU. I was trying to cope with roving bouts of mental distress and psychotic episodes. It was still not clear to me whether the nurses and physician were trying help or kill me. I lobbied my way off the ventilator and out of the ICU before my physicians thought it desirable. Hence, my belief that taking critically ill patients as autonomous agents—part of the “decision-making team”—fails to respect the precarious position such patients find themselves in.

Indeed, once I was moved to the ward, I found myself wishing I were back in the oasis of the ICU. I also lobbied to get myself out of the ward after just a couple of days, despite this too being thought to be not a wise idea.

I was allowed to leave. No doubt I was a difficult and strong-willed patient. But perhaps I should not have been taken to be an autonomous, competent decision-maker, and my strong wishes should have been over-ridden. Nonetheless, I was on the way home, with all that entailed. In the absence of post-ICU clinics, it entails being set adrift, with countless issues to cope with, some serious and frightening.

The fact that even ICU delirium and cognitive impairment are so difficult to assess and have such a tremendous impact on outcomes is enough to give one pause about how well we are able to tell how the most vulnerable of patients are doing.

*Dr. Cheryl Misak was a patient speaker at the ATS 2014 International Conference in San Diego.*