

RAISON D'ÊTRE

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I work in a busy, high-tech critical care unit in the neuroscience department of a large metropolitan medical center. Patient turnover is very high: the majority of our patients are post-surgical patients who are admitted overnight for neurologic monitoring. Sometimes up to ten patients, almost half of our unit, are admitted per day and discharged the next morning. In this constant whirlwind, it is difficult to recall weeks, even days, later the details of any one patient's stay. Granted, some patients do stay with us for prolonged periods, sometimes even for months.

I do tend to remember the chronic patients well. Patients whose illnesses were medical mysteries, patients who had miraculous recoveries, and patients whose intensive care unit (ICU) stay was marked by ethical quandaries are also memorable. Harry was a patient I remember well.

Harry was a retired military officer in his 80s with a recent diagnosis of myasthenia gravis. He suffered a myriad of near fatal complications during an ICU stay at a hospital in a distant city. His diagnosis was not at all a mystery, and the only baffling question was how indeed he managed to survive, among others, a massive retroperitoneal hemorrhage with hypovolemic shock, a cardiac ventricular tachyarrhythmia, a bout of acute cholecystitis, and multiple severe episodes of sepsis that required prolonged use of vasopressors. After three months at the other hospital, Harry's family requested that he be transferred to the ICU where I was on staff. Why? Due to our prominent international standing, they had complete faith in our ability to cure his myasthenia gravis - which, as is evidenced by the list above, was the least of Harry's problems.

In my mind's eye, I saw multiple red flags go up as Harry's attending physician detailed over the telephone the status of each of his failing systems. So much had happened to Harry medically, that the possibility of his ever leaving the ICU was slim, even under the best of circumstances. His ever-regaining independent function would be nothing short of miraculous. Furthermore, we would not be able to add anything meaningful diagnostically or therapeutically to the care he was already receiving. But Harry's family was insistent, and the transfer took place. The last words from Harry's physician to me were a somewhat unexpected "God be with you."

Over the next eight months in our ICU, Harry suffered yet more medical complications, and his relentless physiologic downward spiral continued. Harry, unlike most of our chronic patients, was not encephalopathic or in a coma. He was mentally competent to make medical decisions, and we felt that it was important to determine what goals of care Harry wished for himself in his final days. Inexplicably, Harry abrogated his decision-making powers and named a family member as his ultimate spokesman. The decision-maker insisted that Harry remain full code and that aggressive medical care continue despite ongoing medical setbacks and, by now, the infinitesimal probability that he would ever leave the ICU.

Throughout Harry's stay with us, I was very troubled by his situation. I felt that because his prognosis was extremely poor, aggressive medical care, with its multitude of

invasive procedures that would not cure him, and the demoralizing, debilitating, dehumanizing nature of prolonged ICU stay, were cruel punishment at the end of life. Furthermore, I was not certain whether the decision-maker had Harry's best interest at heart or, frankly, whether he even knew what Harry's end-of-life wishes were. And why did Harry entrust this particular person, who seemed rather detached and cold, with his decision-making? Perhaps the answer was as simple as Harry's own feeling of powerlessness in this dire situation. Perhaps it was Harry's fear of addressing end-of-life decisions head on. Perhaps it was his belief that the designated decision-maker, being a physician, had the requisite knowledge base to make better medical and end-of-life decisions. Harry remained stubbornly silent on these points.

During the eight months of ongoing struggle for his life in our ICU, hardly anyone came to visit Harry. He could not hear (due to aminoglycoside toxicity), talk (due to requirement for continuous ventilator support), or do anything that I considered meaningful. When Harry was healthy, he had apparently liked to play poker, and someone at some point had brought him a pack of cards. But the nurses and physicians in our busy ICU could hardly play cards with him, so the cards mostly lay untouched at his bedside. I could not help but wonder: What was Harry's *raison d'être* these days? What motivated his desire to stubbornly live at all cost, no matter how bleak his existence? One day, during one of the increasingly more frequent, and each time more severe, medical setbacks, the resident and I worked for most of the day to maintain Harry's oxygenation and blood pressure. I was sure that this was the final code, the final attempt at saving his life. At one point, because his blood pressure was very low, he stopped responding to us. By evening, we had made some progress with the vasopressors, and his hemodynamic parameters were finally reasonable. Over the next hour, Harry started to wake up. He indicated that he wanted to communicate and began to write on the clipboard. The resident who had just fought to save his life was at the bedside. She could not decipher his scribbles. He finally printed "WORRIED." Was he worried he couldn't breathe? Was he worried by all the activity around him? Was he worried about his prognosis, his quality of life? Was he worried about his family? Was he worried that he was dying? What was he worried about? The resident tried to coax the answer from him. Harry wrote "C." Then "N." "CN?" What did CN mean? The resident and I were stumped and frustrated. Here Harry was, finally trying to communicate with us, possibly trying to make end-of-life decisions, and we could not understand anything. Was it our inability to comprehend or had the bout of cerebral hypoperfusion finally taken its toll on his cognition?

Harry's nurse walked into his room at this time. She glanced at the clipboard and said, "Oh, CNN. He is worried about the war in Iraq. He just wants to watch CNN. He likes watching CNN and especially the reports from Iraq." Incredulous, I looked at Harry. Was this the answer to the philosophic scuffle that had been going on in my mind for the past eight months? Was this the answer to my nagging doubts about whether I was doing the right thing as a physician and a human being by following the proscription of Harry's decision-maker? Was CNN's reporting on the war in Iraq the retired military officer's *raison d'être*? Was it as simple as that? The nurse switched on the TV and found CNN. Harry nodded "yes."

Harry watched CNN for five more days. In those five days, the Middle East had become an even scarier place for the US military and visitors from the West. Terrorist

attacks intensified, hostages were captured, and Western reporters were publicly executed. In those five days, we struggled and could not find yet another antibiotic to fortify Harry's regimen. He finally succumbed to the multiple resistant infections he harbored, probably in part as a result of immunosuppressive therapy for myasthenia gravis. He died in our ICU with our nursing and medical staff, but no family members, around him.

I have often thought about Harry and pondered about what I should have learned from taking care of him. What was Harry's lesson? Perhaps it was that physicians should not second-guess their patients' end-of-life decisions even if they don't understand the rationale behind them. Perhaps it was that sometimes individual patients' *raison d'être* are unpredictable, extremely personal, and very simple indeed. Still, I feel dissatisfied with these answers: the almost year-long ordeal required to ineffectually prolong Harry's life somehow does not seem justified to me, even though, for all intents and purposes, it was consistent with Harry's wishes.

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