Right Brain: Home is where the heart is

Evan K. Noch, MD, PhD

Correspondence to
Dr. Noch:
ekn9001@nyp.org

Home. Few 4-letter words can be more haunting, and at times, more impossible, to a physician. “I want to go home.” These were the words that were on 3-second repeat 3 days before my 66-year-old patient died in the intensive care unit (ICU). Whispering in a rumbling murmur, barely audible, my patient’s voice was still fervent in its desire to connect, to inform those in his company of his wish.

For days, we did not know what was wrong with him, or perhaps we knew what was wrong but did not want to admit it. He had chronic lymphocytic leukemia and had already undergone transplant and subsequent rejection. But now he presented with multiorgan failure without an identifiable cause. Antibiotics were not working, dialysis only temporized his progression, and diagnostic tests did not reveal a culprit. However, at the end of a long ICU day, our team knew that he was a patient that we could not cure.

His family huddled in his room, holding vigil over their patriarch, already reminiscing over his ability to make each of them feel that he or she was the most special person in his life. He was loved, adored by his family, coworkers, and friends. He always gave of himself, making it all the more difficult to grapple with the impending loss.

As physicians, we diagnose and treat numerous maladies in our patients, often ignoring the global history of present illness before us. When we encounter a complicated case, we roll up our sleeves, and we systematically dissect their ailments on subway and car rides home. The difficult cases keep us up at night. We wonder if we are missing something.

Yet what we do not often ponder in these late-night contemplations are the human beings in front of us, their hopes, their fears, and most importantly, their perspective. More than goals of care, patients bring to the hospital their view of their underlying illness, often radically different than our own summation.

They may see their complaint as serious, as minor, or at times, may wholly ignore significant symptomatology. They may come to the doctor or to the hospital quickly or may linger at home until the end stage of their illness, when bedrest fails their body. As

physicians, our role is to negotiate the muddy waters between often divergent views of their best interest. But more difficult is to align ourselves with their own intuition, ignoring our years of training and deferring to their years of training in the study of their own bodies.

Like a mechanic, we admit the patient to work him or her up and hopefully return the patient as good as new, or as good as baseline, to return to a life already in progress. We may know what is wrong with his or her body, or if not, we can run diagnostics to find the broken part. But what happens if in the process of diagnosis, the patient suffers?

Often, suffering is specifically what the patient seeks to avoid, and is often the reported reason for not coming to a hospital. Largely, the reason for this decision-making algorithm on the part of the patient deals with the fact that the hospital, and in this case, the ICU, is remarkably unlike home. There is no familiar wallpaper, no nostalgic scent emanating from the kitchen, and no neighborhood noises that remind the patient of his or her surroundings. Instead, the patient’s space is invaded by a seemingly ongoing onslaught of unfamiliar staff, inharmonious beeping from throughout the room, and cutaneous bodily injury in the form of fingersticks, blood draws, and IV lines. It is therefore no wonder that many patients avoid the hospital at all costs.

Each time I entered my patient’s room, I wondered what I could say to him, to his wife, to his 2 adult children who lingered at his side. My response, with all I could muster, was “You cannot go home.” Home is where the heart is, or where his heart should have been. But his heart was sustained by 3 bags of pressors; it would not survive the ambulance ride home.

Initially, our team’s goal was to identify the cause of his deterioration, to repair the problem, and to send him on his way. Yet, as time progressed, my goal became synergistic with his own: to send him home as soon as possible, regardless of the eventual clinical outcome.

I wondered if all we had done to extend his life in the hospital was truly caring for him. What are a few

From the Department of Neurology, New York-Presbyterian Hospital, Weill Cornell Medical Center, New York, NY.

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more days in the ICU compared to a day at home? What is the metric conversion of home to ICU? How many high-decibel ICU days equal the silence of home?

I encountered another patient in the neurologic ICU, a 36-year-old man with a newly diagnosed brainstem glioma, who presented for resection. He was just at the beginning of his oncologic journey, and had many options at his disposal. His resection was largely successful with no radiologically visible disease present in his pons. However, he encountered numerous postoperative complications, including significant dysphagia and ventilator dependence.

Given that he was just 36 years old with an essentially incurable disease, our team's and the patient's goal was to discharge him home to enjoy as much time as possible with his family. He and his family decided to pursue tracheostomy and percutaneous gastrostomy in order to fulfill this goal. Yet his course was complicated by persistent tube feed aspiration, requiring multiple revisions to his gastrostomy, nearly fatal pneumonitis, and another month in the hospital. He eventually was discharged to a skilled nursing facility. Whether he would improve with subsequent radiation and chemotherapy was not of immediate concern; we knew more inpatient time would not improve his quality of life.

In the case of my first patient, it was not entirely clear to me that we were caring for him. He knew that he had precious few days left, and so did we. He endured a barrage of tests, lines, and treatments meant to care for him, but this diagnostic workup was futile in the end.

In retrospect, I wonder if every member of his health care team—nurses, technicians, medical students, physicians—would have said that he never should have come to the hospital. I imagine that the patient also felt that way. What we gave him was not the gift of life; we did not provide more days, but instead, arguably less quality time with his family. Whatever home represented to him, his ICU room was not that.

In the case of my second patient, we actively tried to send him home right from the first moments of his admission. Though his course of complications was not unexpected given his underlying diagnosis, it is conceivable that he may have chosen not to even undergo the first surgery if only to avoid the

subsequent prolonged hospitalization. If he could have seen the future at the beginning of the journey, what future would he have chosen for himself?

These cases are a mere example of numerous instances where personal removal and distance from a difficult health care scenario provides critical benefit. In this case, I wonder, is ICU care really caring? And if not, when should we stop caring, or rather start caring for our patients, sending them home, greatly daring?

As physicians, our own vulnerability is often the barrier to achieving our patients' goals. Our role in these complex health care decision algorithms is to use our experience to transform patients' objectives into reality. Our own need for validation in arriving at the correct diagnosis is often at odds with a patient's desire to return home. Thus, the most appropriate use of our time in caring for our patients may be merely to return to the beginning and ask, "What brings you to the hospital and what do you hope to achieve from your stay?" Receiving answers to these simple questions allows us to formulate a plan to achieve these goals, whether it means imminent discharge or reasonable workup in the framework that they provided.

Empowering our patients to formulate their own plan of care can also restore control at a point in their lives when much of their control has been lost. And placing our patients in control may allow us to let go of that critical diagnosis, not to breathe an inward sigh of defeat for not finding the answer, but rather to reap joy by focusing our attention on the centerpiece of the case: the patient. As providers, deferring to the vision of our patients provides comfort, satisfaction, and reassurance that whatever the clinical outcome, our patients chose for themselves how to spend the rest of their days.

Home. Few 4-letter words are now as meaningful to me. We must treat not the illness, but the patient. As I contemplate the oath that launched my career as a physician, to do no harm, I will always remember: a spoonful of home is sometimes just what the doctor ordered.

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