

FROM THE INSIDE



My wife's turn in the ICU

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For 30 years, I have been a pediatric intensivist in a world-renowned university hospital. On June 10, 2018, I entered the bewildering world of the intensive care unit in a new role as a husband of a patient. For the prior year, my wife, Fay, had been under treatment for diffuse B cell lymphoma (DBLC). She had clearly not been doing well after the latest attempt to control her disease with an infusion of gemcitabine and oxaliplatin a few days before. She had marked abdominal and back pain. On that morning, she collapsed.

Upon admission to our local hospital (not the one that I am affiliated with), the intensive care attending was kind enough to show me the imaging studies which clearly showed that her stomach was greatly distended, the likely culprit of her pain. He explained to me that he needed to call in a GI consult to determine the need for placement of a nasogastric tube to relieve the gastric obstruction. It was a Sunday; hence it would likely have meant many hours until the consultant came. I looked at him and asked, “Do you really need a GI consult to place an NG tube, why can't the nurses do it now, my wife is in great pain?” Seemingly instantaneously, the nursing staff were able to place the tube without much difficulty, 3 l of gastric content was drained, her stomach shrank, and the pain went away. I wondered, how would families have the knowledge to question the need for a consult for a routine procedure, which in this case instantaneously removed her pain, avoiding many hours of suffering?

By the next day, her kidneys began to fail which soon required continuous renal replacement therapy. Every 30 min, the dialysis machine went into self-check mode accompanied by a piercing alarm, most loudly of course at night. Why this mode needs an alarm is a mystery that only a biomedical engineer could answer; there is no

action item on this alarm by nursing staff. It is sort of like the machine feeling lonely and needing to call attention to itself. Why should patients and family members, let alone staff, need to suffer from this alarm q30 min 24/7? Thankfully, after discussing the alarm noise with the staff, one of the nurses knew how to dive deep into the menus on the machine and was able to shut it off, bringing back the “sounds of silence.” Noise is known to be associated with ICU delirium [1]. I highly doubt that many families would even question if this alarm could be silenced.

Participating in rounds each morning as a family member, and not as a physician, was an eye-opening experience. Although everyone on the team was caring and kind, the misinformation that was regularly presented was staggering. I wondered about my own practice of conducting rounds. How often is the information that is presented incorrect? How could I going forward find ways to reduce the risk of misinformation being presented? I recommend that a family's observations need to be incorporated in the presentation of the patient during rounds.

After the first weeks in the ICU, we were moved to the floor on a non-teaching service, introducing us to a new concept, waiting for the doctor. On a resident service there is always someone around, and in truth both for my service and theirs, 99% of the needs can be addressed by the intern. But without house staff, one became afraid to leave the room and miss the physicians—not exactly an ideal situation. Why cannot the physicians make it known each day what time they would be by so the family can make whatever arrangements necessary to be there?

Two days before she passed, Fay lapsed into a coma as the lymphoma spread unchecked. I was approached by the fellow for a Do Not Resuscitate discussion the day before her death. By the next day, it was clear that there

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was truly no hope for recovery, which meant stopping the dialysis and stopping the pressors, so she could die naturally (she was not on a ventilator). There was no suggestion of removing the dialysis so that she would not need to be attached to a machine, no concept of removing the blood pressure support, or what to do to ensure that she was comfortable. My daughter had to ask, “Dad, if Mom is not going to live, why do we need to have these pumps in the room?” Why did it take the patient’s child to assess that having these machines in the room were not in her mother’s best interest? Perhaps, suggesting what might make the patient more comfortable during their last hours should be a role of the treating team.

Two final notes about my experience. First, in the month that Fay was in the hospital, almost all of it in the ICU, not a single individual from the institution made a point to come to the bedside and ask how my children and I were doing. Fortunately, I had family, friends and community, as well as clergy, to aid me. I know, however, from my own experience that many patients and families do not have any support, some patients do not even have family. Why not institute a long-term care team who regularly checks on the loved ones to see if their basic needs are being met, to show the institution cares about them? Second, once it has been determined that the end of life is approaching, the families need to speak to the attending physician, not only the fellows and house staff. Perhaps, the greatest lesson I have learned from this experience is that when any physician loses a patient, the family need to see and hear from you.

Some of the lessons and observations told here have changed my practice and have given me a new appreciation of what my patients and their families go through. The little things like the noise, the bureaucracy, and

the inattention, all contribute to the burden of suffering and patient and family dissatisfaction. A little touch of sensitivity, at very little cost, for those of us who care for patients in the acute care setting, can go a long way, just like the simple act of silencing the dialysis alarm. I was often overwhelmed by all of this, how much more so others? Families are an integral part of the medical team, just as important as the doctors and nurses. They spend so much time in the hospital room, they note every change in condition, and they need to have the ability to participate in the care with the medical/nursing service. I believe that every hospital needs to create mechanisms for families to partner with their health-care providers to ensure that their loved ones get the best care possible. Is that not what we all swore to do when we first put on our white coats? It is time we take the families’ perspective into consideration.

Compliance with ethical standards

Conflicts of interest

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