Challenging Family Dialogues within the Intensive Care Unit: An Intensivist's Perspective

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To the seasoned intensivist, discussions with family members of critically ill patients in the intensive care unit (ICU) can be very predictable. However, this does not imply that these dialogues are straightforward or simple. Each day, we spend a significant amount of time meeting with family members at different stages of their loved one's ICU stay. Some family members are satisfied with these exchanges while others leave them distraught or in emotional shambles. At times, intensivists do not always effectively communicate with family members. ¹⁻³ Both the team and the families come to the "ICU table" with different sets of perspectives, expectations, conversational skill sets, life experiences, and tolerances for stress. These differences are magnified when the ICU course turns rocky.

We thought it useful to illustrate ICU dialogues with family members as we perceive them. We focus on the potential checkpoints where miscommunication and misunderstanding may occur throughout the roller coaster ICU experience. To this end, over the past few years, our Critical Care Medicine group has been collecting thought-provoking comments from various family conferences. Herein, we present the dynamic phases of an ICU encounter contextually inserting relevant quotes.

The specter of a loved one lying helplessly in an ICU bed, attached to imposing machines, with tubes coming out on all sides can be quite numbing and frightening. No amount of schooling or training can really prepare a person for this emotionally taxing situation. Disbelief reigns! We frequently hear, "How can a person go from being fine one day to being so sick the next?" or "He was shoveling snow just last week!" or, "She was just fine after surgery, talking, walking, and eating."

Not only is the ICU a strange and scary place, but oftentimes, in the midst of our first meeting with family members of newly admitted ICU patients, we quickly realize that they are not really sure who we are or what we do. It seems to us that Critical Care Medicine as a medical specialty suffers from a lack of brand recognition. Often the family members say, "You're a what? An intensivist?" "We've never heard of an intensivist." "Do

team.

you also work in the Emergency Room?" "I heard someone mention critical care, is that the same as intensive care?" Or sometimes we get whacked, "What about getting a real doctor, like a cardiologist or a pulmonologist!"

Family members immediately find different ways to let us know how much the patient means to them. They try to impress upon us the vitality and unique nature of their loved ones in the hope that this will make us all work harder. "He's a real fighter and never gives up." Or "He's a young and healthy 90." Or "You have to take extra care of her, she's very special, she's the mother of eight children." Sometimes political or social connections are used to further incentivize or push the ICU team. "He's best friends with Mr. Z who is on the Board of Trustees, or "She's friends with this or that politician."

But, Google has really altered the nature of our family discussions; everyone, it seems, can now be a doctor. We used to hear "I'm not a doctor, but ..." Now, the inevitable internet search leads to "I've been doing some reading on the web about this new drug and I've heard that it's a wonder drug. Why isn't my mother getting it?" Or "What is the APACHE III score of my sister and how are you using this value?"

Just as intensivists regularly look at reams of lab data and calculate all types of organ failure and prognostication scores, family members similarly reframe the ICU discussion to a "numbers" game. This approach to seemingly getting our arms around the complicated "big" picture is used in many aspects of our lives, whether tracking our retirement portfolios or determining the odds of next week's football game. "Doctor, what are her chances for improvement - 50/50, 30/70 or 80/20? Even one in a million?" Over time, family members even become experts at looking at the bedside monitors and devices. "I've been watching the numbers, I see that the heart rate is down and you were able to decrease the oxygen on the respirator to 80%, and the blood oxygen is still over 90%, so my father must be better, right?"

As the days go by, some families become more desperate. They seek good news or even any news from every person they meet. And the ICU environment certainly offers family members a myriad of people with whom to converse. Unfortunately, this frantic search for information leads them to receive conflicting and unreliable data. Frustration results, "Why do we keep getting mixed mes-

sages?" Or, "Doctor, we like the hospital, but why can't all of you get the story straight?" As family members gather together with other patients' families in the waiting room day and night, they often share their ICU stories with each other. We'll overhear someone say, "What about the new antibiotic the patient in Bed 8 is getting? Shouldn't my husband be getting that too?" "I see everyone is gowning up, I keep hearing about that bad Staph bug going around, my father better not catch it."

Occasionally we become concerned, even perplexed, when we cannot successfully convey our message to the family despite our best intentions and efforts. Some families are just in denial; the reality of no progress and/or likely poor outcome cannot be heard, much less accepted. "Doctor, I have been badgered with the truth enough. I just don't want to believe it." Or, "Doctor, don't you ever have any good news to report to us?" The insatiable need for prolonged and repetitive family conferences may deflect time away from the care of other patients and meeting with other families.

Unfortunately, some patients get stuck in the ICU, either not improving, or just steadily deteriorating despite aggressive care. We broach treatment limitation or end of life care with the family as we realize that further ICU care is not going to be beneficial. Sometimes this news is greeted with stunned silence. The family often pleads for their loved one to be able to stay a little bit longer in the ICU, "Let's just see how he does for a few more days or over the weekend." Or, "We just need to buy some more time until everything turns around." Or other approaches are used to postpone the inevitable ICU transfer. "Doctor, our 50th wedding anniversary is in two weeks, so let's continue to keep him in the ICU. "Or, "You can't discharge my mother, she averages 14.5 alarms per hour, how can the ward ever take care of her?"

And then comes the quest for the miracle, "Don't you believe in miracles? Haven't you ever seen someone in this condition get better?" "Are you giving up? We'll never give up!" Or, ignoring the express wishes of the patient, "Oh, Doctor, my father did have an advanced directive, but I'm not sure whether I want to give it to you." Or, the message now gets personal "What would you do if this was your mother or father?"

Such questions highlight the existential dichotomy of critical care. As intensivists, we sometimes have to reconcile the family members' unrealistic view of prognosis, overly hopeful expectations, and desire for endless futile ICU care with our own understandings of prognosis, goals of care, and appropriate use of ICU beds. Where, and when should we draw the line? How do we all let go?⁴

This collection of comments and thoughts reflects a synthesis of many different discussions conducted under diverse conditions. Thankfully, not all of the individual elements of the scenario described above occur with each patient. Family members and intensivists commonly have amicable discourse resulting in an acceptable degree of understanding and consensus regarding the prognosis and care plan. However, on occasion, things just don't go as well as hoped for, neither in clinical outcomes nor in our discussions. While effective ICU communication strategies have been designed and studied, 5-12 even the best of these may not prevent conflict and disagreement. Nevertheless, our challenge as critical care practitioners is to ensure that our dialogues with family members are honest and direct and that we communicate in a timely, consistent and empathetic

Well, onto the next family meeting!

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