



**Case.** Mr. M., aged 75, had lived with postnecrotic cirrhosis for many years, during which time he suffered from ascites and esophageal varices. Over time he developed hepatic encephalopathy and prolonged prothrombin times (unresponsive to vitamin K therapy), his ascites progressed, and he had several episodes of acute esophageal bleeding. He collapsed at home and was brought to the emergency department in a coma by his frightened wife and son. Mr. M. was admitted to the Intensive Care Unit with a urinary tract infection, gram-negative sepsis, and adult respiratory distress syndrome (ARDS). He was placed on a ventilator and received fluids, antibiotics, and pressor agents. He recovered from his gram-negative septicemia and shock, but his mental status deteriorated to the point where Mr. M. became profoundly demented. After another week in the ICU with no improvement either in Mr. M.'s mental status or his pulmonary function, the intensivist called a meeting with the family and recommended that Mr. M. receive "comfort measures only." The family responded with outrage, and insisted that everything be done to prolong Mr. M.'s life. The intensivist called the hospital's ethics committee to request their help with "another family that doesn't get it."

**Discussion.** While specific medical details may change (the details in this case come from a medical ethics text published in 1986<sup>1</sup>), the problem persists: occasionally, family members demand the continuation or intensification of life-prolonging treatments for a relative who, in the medical team's judgment, has no hope of recovery. Most of the time, these conflicts resolve themselves through sympathetic dialogue, so that the patient's death, while sad, is not the occasion for protracted confrontation or recrimination. Sometimes this is not the case. Sometimes staff and families dig in their heels for a prolonged, polarized dispute, and the atmosphere at the patient's bedside is spoiled by suspicion, anger, and resentment.

What determines the outcome of these initial disagreements? And what can caregivers do to increase the likelihood of the first outcome rather than the second? I want to suggest answers to these questions after twenty-five years of medical ethics teaching and consultation in academic medical centers. In my experience, the three most common sources of escalating conflict with "the family that doesn't get it" are: (1) the team's mislabeling of the conflict; (2) overemphasis on facts rather than emotions; and (3) mixed messages to the family from the medical team.

*Mislabeling:* When families and caregivers disagree about life-sustaining treatment, what exactly are they disagreeing about? A differential diagnosis should include at least the following: (a) the patient's medical condition; (b) the patient's own preferences; (c) the credibility and trustworthiness of the team or hospital; (d) the meaning of "care" and "hope"; (e) the legitimate goals of medical care; (f) the characteristics of an acceptable quality of life; (g) the acceptable probabilities of recovery; (h) the acceptable trade-offs between treatment benefits and costs; or (i) the urgency of the need for a decision. Just as definitive

medical therapy usually requires accurate identification of the disease, so does successful negotiation with families usually depend on identification of the important issues to be negotiated.

*Facts over emotions:* In my experience, the team usually stops its differential after (a) above—deciding that the family simply doesn't comprehend just how ill their relative really is—and attempts to remedy the problem with an avalanche of medical explanations. Yet, if the disagreement is actually about one of the other matters, these technical details are completely irrelevant. Even if the medical facts are at the crux of the problem, however, if we do not first notice and acknowledge the strong emotions swirling around inside the family (fear, anger, disappointment, sadness, ambivalence, or all of the above), our mini-lecture is likely to fall on deaf ears. Then, having reinforced our (mis)impression that "the family doesn't get it," we redouble our efforts to make sure they understand the medical facts...and around we go until the ethics committee is called.

*Mixed messages:* During most patients' stays in an ICU they are attended by swarms of caregivers. (This may be why they feel so lonely.) Most of these nurses, technicians, residents, fellows, students, attendings, and consultants see themselves as advocates for the patient, and they are usually willing, if not eager, to provide information and opinion about how things are going. Because each has formed an impression of the patient based on his or her specialty, role, time (and timing) at the bedside, and philosophy of "good" care, the family's impression is likely to depend on who has spoken to them most recently or convincingly. The family that "doesn't get it" may have simply drawn an appropriate and rational conclusion from data presented by one of our colleagues a few hours before.

*Closing suggestions:* In my experience, intractable conflicts with families over life-sustaining treatments are very rare. The family that doesn't "get it" is even rarer, if we intend that condescending phrase to describe relatives who are incapable of comprehending or entertaining the implications of a grim prognosis. Some rules of thumb may prove useful for preventing unwanted escalation of conflict: (a) If there is a disagreement, try to be clear on what it is about. (b) Name and respect the family's emotions (and our own). (c) Verify that all team members agree on the prognosis, the balance of risks and benefits, and the patient's goals (if known). (d) Channel communication with the family through the person whose rapport and credibility are greatest. (e) Remember that in complex and stressful situations, the first aim of communication is to establish trust.

#### Reference.

1. Jonsen A, Siegler M, Winslade W. *Clinical ethics*. 2<sup>nd</sup> ed. New York: Macmillan, 1986.