
Part II

Decision-Making: Families in the Mix

Our ethical principles and processes are predicated on respect for persons, and a call to honor the autonomy of competent adult patients. Patients who have the cognitive ability to understand, communicate, and decide for themselves can make whatever decisions about medical care that they want to: Physicians and other medical care providers are obligated to honor even treatment preferences they feel are unwise, including those that will lead to the patient's death. Honoring autonomy even means in some cases that physicians and others end up providing care that they feel is futile, that is, care that has no medical benefit, that might have an effect on the body, but cannot offer a benefit to the person.

These situations are complicated in and of themselves, but additional complexity arises from the fact that most patients are not alone in their decision-making with their physicians, but are accompanied by family members (loving and otherwise) who have their own preferences, opinions, values, and decision-making power. The threat of legal action looms over situations in which a physician refuses to comply with a family members' wishes, even if they contradict what the patient may have told the physician. Patients are not usually isolated individuals who solely take into account their own preferences when deciding about medical care. They are concerned naturally about the effect of their decisions on the loved ones who will soon be left behind to mourn their deaths and agonize about whether their loved one had "a good death."

The cases in this section concern issues such as parents who refuse to accept brain death; the ways the media influence medical decision-making; the distress caused by missed diagnoses; a family's refusal to accept palliative care for their dying son; decisions to remove life support from young patients; how codependence between a patient and family can create obstacles to healing; and situations in which a patient's stated treatment preferences or best interests are not aligned with the opinions of family members.

A short summary of each of the six cases in this section is given as follows:

Case 6—What is the Standard of Care for a Corpse?

A mother inadvertently gave her young daughter expired insulin and told the Emergency Department physicians only that her daughter was experiencing flu-like symptoms. She refused to allow her daughter to be removed from life support even after she was declared brain dead, and threatened the hospital with a lawsuit for failing to accurately diagnose her daughter's condition in a timely way.

Case 7—When the Palliative Care Team Got Fired

A 17-year-old African American man was admitted to the hospital with Stage IV metastatic colon cancer, a recurrence from 5 years previously. His mother was very religious and was at his bedside constantly, and answered all questions directed to her son by the medical team. She had faith in God and in her son's oncologist, who she believed previously cured her son's cancer. The palliative care team was forbidden to enter the patient's room after they described his extremely poor prognosis and the possibility of transitioning to comfort care only.

Case 8—A Young Woman's Wish to Die

A 19-year-old Hindu woman was admitted to the PICU of a large urban hospital after an automobile accident. She was ventilator-dependent and quadriplegic and had clinically significant depressive symptoms. The patient's uncle was the family spokesperson and declared that all life support must be stopped since the young woman's injuries were a result of karma from a past life.

Case 9—When Parents Contest an Adult Child's Advance Directive

The patient was a 25-year-old woman admitted to the hospital from hospice care with end-stage cardiomyopathy. She had an advance directive which specified a limited trial of ventilator support, which the patient's schizophrenic mother successfully contested in court.

Case 10—Please Stop Torturing Me—Unless my Wife is in the Room!

A 55-year-old well-known attorney was diagnosed with B cell lymphoma. The aggressive treatment caused the cancer to go into remission but led to multiple system organ failure. The patient's second wife insisted on continuing treatment, which included dialysis and other invasive procedures, partly because the oncologists told her that her husband's cancer had been cured. The intensive care team (and sometimes the patient) saw continuing treatment as futile, but were not able to convince the patient's wife to agree to any other goals of care.

Case 11—Who Should Make Treatment Decisions for a Battered Spouse?

The healthcare team struggled with how to reconcile American law, Western medical ethics, and their own cultural values when a woman who was a Chinese immigrant was brought to the hospital after being brutally beaten by her husband, and her husband was permitted, at least initially, to act as her proxy decision-maker.