



Center for Health Ethics
Health Management and Informatics
University of Missouri

David A. Fleming, MD
315 Clark Hall
Columbia, MO 65211

January 2004

Ethical Issues: The Difficult Family

Recently I visited my 90-year-old mother who had been hospitalized for aspiration pneumonia. Like most frail elderly folks with chronic disease her initial chances of recovery were low, and during the first 24 hours the other family members and I were less focused on the treatment of her pneumonia than on ensuring comfort care and dealing with the expected outcome. But mom beat the odds. After a week she is alert and eating, and full recovery seems likely. Because death was now less eminent, our treatment goals as a family have become more focused and our demands on the health care team have increased. As expectations shifted from eminent death to probable recovery we wanted to move things along as quickly as possible and get her back to the nursing home so things could “get back to normal”. We all have busy lives and, all things considered, this seemed logical. But is our agenda in our mother’s best interest?

Some of the most difficult situations faced by physicians have been when loving and caring families, often out of guilt or misunderstanding, disagree or become demanding. This challenge intensifies when those demands do not seem to coincide with what seems to be in the best interest of the patient. This is particularly true in end of life care when conflicts between physicians and families often create emotionally difficult and time consuming situations for everyone involved in the care of the patient.ⁱ There are many factors that can potentially lead to such conflict, most of which derive from barriers in communication.

Bad news is poorly processed and imperfectly remembered by most people.ⁱⁱ Families may not understand what is happening because they aren’t as yet prepared to hear the patient’s diagnosis or prognosis. The grief that ensues from receiving bad news may be severely debilitating and the initial denial becomes a powerful coping mechanism. Physicians who misinterpret denial as poor understanding may respond by attempting to state the medical facts more explicitly, a strategy that is often met by a greater wall of denial or even anger from the family, further frustrating and alienating the provider who thinks, “they refuse to listen.”

Guilt may also contribute to unwillingness by family members to participate in certain decisions, and may be tied to a long and complicated personal history with the patient, underscoring concerns about abandoning a loved one. Invariably the family member who has been the most distant or who travels the furthest to be there for the patient may be the one who leads the charge to ensure that “everything is done” for the patient. Families can be misled by information from multiple sources, such as TV, the Internet, friends, and relatives, which more times than not generates further confusion when the multiplicities of sources disagree.

The question of secondary gain for surrogate decision makers or a gap between the physicians' beliefs and those of the patient or family may also become a source of major conflict. Pellegrino makes it clear that the moral authority of the patient, the surrogate, or a health care directive is not absolute.ⁱⁱⁱ Legitimate economic pressures may influence certain decisions of patients or surrogates. But when the physician is asked to violate personal or professional integrity, or when the goals of the surrogate are clearly self-serving to the detriment of the patient, the physician is under no obligation to comply with such a request or demand.

Physicians also have a propensity to create communication barriers. Talking and explaining takes time, which is at a premium. They may be uncomfortable with prognostic uncertainty and hedge information or recommendations, leading to confusion or false hope. Physicians may also be uncomfortable discussing death or troubled by the thought of a medical "failure" and thus avoid such discussions, leaving the patient and family clueless. Lack of confidence or errors resulting from knowledge and skill deficits may also lead to conflict with the family when mistakes occur or wrong information is given. Another common behavior is that physicians often use confusing medical jargon, leaving patients and families bewildered. Lastly, in the modern paradigm of health care there are unavoidable and pervasive economic pressures, which can't help but influence decision-making when contracts are influenced by the economic stewardship of the individual writing the orders.

For physicians death and illness are routine, but not so for patients and families who often come to us afraid and confused. Poor understanding, ineffective communication, and lack of sensitivity from health care providers tend to diminish trust and may lead to conflict. In the relationship we forge with patients it is the physicians' responsibility to do everything they can to secure a trusting relationship. Showing empathy and compassion are always important but we must also communicate effectively: sit and listen rather than talk; offer time for questions; when necessary have regularly scheduled family meetings; use easy to understand language and terminology; develop a shared awareness and understanding of the patient's treatment goals; when necessary be open about your own limitations, values, and beliefs. In short, find time to talk.

ⁱ Goold S, William B, Arnold R. Conflict Regarding Decisions to Limit Treatment: A Differential Diagnosis. *JAMA*. 2000; 283(7): 909-913

ⁱⁱ Buckman R. *How to Break Bad News: A Guide for Health Care Professionals*. Baltimore, MD: Johns Hopkins University Press; 1992

ⁱⁱⁱ Pellegrino E. Decisions to Withdraw Life-Sustaining Treatment. A Moral Algorithm. *JAMA* 2000; 283(8): 1065-1067