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## Guest Editorial

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# The Family and Terminal Care Decisions

Howard Brody, MD  
East Lansing, Michigan

I am grateful to John E. Arradondo, MD, for sharing an anecdote, which goes roughly as follows. Joe, an elderly man, was seriously ill and unable to communicate, and the physicians were debating two possible treatment options. Joe's sons and daughters had all gathered in the hospital, and the group was split down the middle, with each half arguing loudly for one treatment option and denouncing the choice of the other half. The physicians were desperately trying to establish some consensus, but despite several group discussions no one appeared to budge on what they thought was best for their father. Finally one physician asked a question no one had thought of before: "Who is your father's best friend; who, in his own generation, knows him the best?"

The children could not agree on treatment, but they could readily agree that old Sam was clearly in the best position to know their father intimately. So the physicians sent for Sam, and asked him, "Now that we have told you the medical options, what do you think Joe would have wanted us to do?" And Sam unhesitatingly replied, "Joe would say, do this." When the physicians told the children of Sam's view, they thought about it and admitted, "Yes, that does sound like what Dad would have said." They could now readily concur on one plan of treatment.

While perhaps demonstrating an atypically "happy ending," this anecdote supports some aspects of working with a family around a terminal

care decision that are addressed by Erstling in this issue of the *Journal*. Depending on generational distances and other aspects of family life cycle and family function, family members are sometimes not in the best position to make decisions on behalf of their sick relative, and sometimes their demands to participate are inversely proportional to their ability to do so effectively or wisely. The role of the family as substitute decision maker needs to be carefully distinguished from the role of the family as a source of data about the values and life goals of the sick person. Even where the family is not placed in the role of substitute decision maker, the members can serve as a sounding board to check on the validity of the decisions of others. And, if asking one question leads to conflict or impasse, thinking of a different question to ask may allow for progress and consensus.

Erstling thus shows us how a knowledge of family systems, and some basic family assessment and family intervention skills of the sort that ought to be part of family practice residency training, can aid the physician in the realm of decisions for the terminally ill patient. She bases her recommendations both on currently accepted principles of family dynamics and on recently articulated principles of medical ethics. Other issues regarding the role of the family in terminal care decisions are, however, much less well articulated and deserve further study.

First, the moral status of the family in demanding a role in these decisions remains unclear and has been seldom investigated despite the now-extensive literature on medical ethics. One widely cited ethics manual,<sup>1</sup> as well as a report of the President's Commission,<sup>2</sup> suggests strongly that

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From the Department of Family Practice, Michigan State University, East Lansing, Michigan. Requests for reprints should be addressed to Dr. Howard Brody, Department of Family Practice, Michigan State University, B100 Clinical Center, East Lansing, MI 48824-1315.



family members ought to have relatively little say in how the physician cares for an adult patient, except to serve as a source of information about that patient's previously expressed values and wishes. Yet these counsels are contradicted by everyday hospital practice (perhaps motivated primarily by liability-avoidance considerations) in which the directives of the family of a no-longer-competent patient are slavishly followed. Further, some have argued that the current emphasis on the "best interests of the newborn" in neonatal decision making inappropriately excludes concern for important family burdens, which deserve at least some consideration.<sup>3</sup> The role the family should play in various ethical decisions under various circumstances thus deserves much more extended analysis.

Ideally this ethical analysis would proceed in tandem with legal investigation for the "defensive medicine" reasons already cited. It may be true that the family members of an adult patient have little or no legal standing as substitute decision makers,<sup>1</sup> but they are the most likely potential litigants if there is later dissatisfaction with the physician's treatment. If the advice of *Erstling* is followed, the resulting emotional climate is likely to make a negligence suit a low-probability event. However, specialists in family law may help us to clarify the precise legal role of the family and how this role may vary among jurisdictions and as a result of recent legislation or court decisions.<sup>4</sup>

Many terminally ill patients in hospitals and intensive care units will be cared for by physicians who have no formal training in the assessment and intervention techniques that *Erstling* describes. How can a family medicine department or a team made up of family physicians and family counselors offer appropriate consultation services in this setting? Increasingly, such matters may be referred to some sort of institutional ethics committee.<sup>5</sup> Not unusually, a request for psychiatric consultation turns out on examination to be a disguised form of raising an ethical dilemma<sup>6</sup>; in the same vein, cases may be referred to a hospital ethics committee when the services of a family assessment team might be of more practical benefit. Will hospital ethics committees have access to these sorts of teams, and what sorts of consultation arrangements will help resolve these problems to everyone's satisfaction?

Finally, another skill of the experienced family physician seems pertinent to these problems, but is seldom explicitly addressed. The family physician is supposed to be an expert in the natural history of diseases and of personal life changes. We are finally becoming more comfortable with the recognition that the physician's role in terminal care may be the management of death. The patient is dying anyway; the physician may have a little control over how the patient dies and a little less control over the time of death, and the ability to predict the approximate time span for death will be of great assistance to the family as they try to prepare and to carry out their tasks of grief and transition. At the same time the physician has a sense of the pace of the patient and family—how slowly or how quickly they are moving through the work of grieving, separation, and acceptance.

When we speak of a "good death" or a "natural death," often we mean that chance or the physician has conspired to coordinate the time line of the patient's illness and the time line of the family's psychological tasks. Bad outcomes occur when the patient dies suddenly before the family's grief work is fairly started, or when both patient and family are ready and have said goodbye and yet the patient lingers on in a meaningless and frustrating limbo. If we assume that active means to hasten death are not appropriate, is a "good death" of this type a matter strictly of serendipity? Or are there ways for the skillful family physician to facilitate such an outcome without resorting to unethical practices? These final services to our patients deserve more explicit discussion and guidance.

## References

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