

Making Decisions with Families at the End of Life

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Because advance directives are not yet the norm, end-of-life decisions for patients without medical decision-making capacity are made regularly within discussions between the patient's physician and family. Communication and decision making in these situations require a complex integration of relevant conceptual knowledge of ethical implications, the principle of surrogate decision making, and legal considerations; and communication skills that address the highly charged emotional issues under discussion. The most common pitfalls in establishing plans of care for patients who lack decision-making capacity include failure to reach a shared appreciation of the patient's condition and prognosis; failure to apply the principle of substituted judgment; offering the choice between care and no care, rather than offering the choice between prolonging life and quality of life; too literal an interpretation of an isolated, out-of-context, patient statement made earlier in life; and failure to address the full range of end-of-life decisions from do-not-resuscitate orders to exclusive palliative care. (*Am Fam Physician* 2004;70:719-23,725-6. Copyright© 2004 American Academy of Family Physicians.)

✉ **Patient information:** A handout about end-of-life choices, written by the authors, is available on page 725.

ACE This article exemplifies the AAFP Annual Clinical Focus on caring for America's aging population.

Increasingly, medical and lay communities have called for patients to establish advance directives for medical and end-of-life decisions, including a living will, designation of a proxy with durable power-of-attorney, or a medical directive established with a physician. Unfortunately, as few as 20 percent of patients who lack decision-making capacity have advance directives.^{1,2} Thus, physicians frequently must make critical medical decisions with close relatives without direct input from the patient. With an admission of an elderly, semicomatose patient in septic or cardiogenic shock,³ the physician must establish decisions about medical care with the family.

Recent literature addresses the communication issues that arise when discussing such decisions with competent adults.⁴⁻⁸ When the patient lacks decision-making capacity, the physician must discuss end-of-life issues with the family members of these patients. The legal, ethical, communication, family, and decision-making issues involved become increasingly complex and challenging.⁹⁻¹²

This article identifies the special characteristics and demands of establishing end-of-life plans of care with the families of patients who lack decision-making capacity, and recommends a set of communication

strategies for such discussions. Failure to consider and address the intricacies of these interrelating factors can lead to decisions that are contrary to the values and preferences of the patient and may create tension for all involved.

Key Concepts and Definitions

For effective decision-making consultations, physicians should address the following concepts and principles directly and explicitly.

SUCCESSION OF RESPONSIBILITY

If there is no advance directive, the physician's first challenge is to determine whom to approach about critical care decisions. While families frequently choose to involve a large number of connected relatives in these discussions, it is useful to define who has "final say." Some states have enacted legislation that clearly defines the hierarchy of decision makers, and state law should direct these decisions when applicable. Without legal guidance, the most frequent hierarchy is the spouse, then the adult children, and then the parents.¹³ Physicians should encourage the decisions that best incorporate the patient's values, realizing that the most appropriate source for this information may not be the next of kin.

SUBSTITUTED JUDGMENT

The family needs to understand the difference between substituted judgment and decisions in the best interest of the patient.¹⁴ Substituted judgment refers to determining how the patient, if able to fully understand his or her condition, would make the decision. Unlike best-interest decisions, in which families use their own values to make the best decision on the patient's behalf, substituted judgment requires the decision makers to put themselves in the patient's shoes, using the patient's values to make the decision. This concept should be reinforced during the interview by reminding family members that the decision to be made may not be the one they would make for themselves or for the patient using their own values. When the family tries to approximate the patient's decisions as closely as possible, the guilt that regularly complicates such surrogate decision making often decreases.¹⁵

CLINICAL SITUATION AND PROGNOSIS

To arrive at decisions appropriate to the situation, those concerned need to share a common appreciation of the patient's condition and prognosis.¹⁶ Early in the discussion, it is important to determine the accuracy of the family's knowledge and their degree of acceptance of the patient's condition and prognosis. It is useful to have family members describe their expectations for what will happen medically with the patient in the future. The physician should be prepared to provide emotional support when family members verbally express, for the first time, the expectation of their loved one's impending death.

If the family's appreciation of the clinical situation differs significantly from the physician's, it usually is not possible to achieve an appropriate plan of care at that time. In the event that the family cannot provide direction, the physician should state clearly the default posi-

tion (i.e., full cardiopulmonary resuscitation) and agree to meet with the family again after initiating efforts to bridge the lack of common ground using additional tests, consultations with experts, involvement of ethics committees, and other resources.

RANGE OF DECISIONS

In the recent past, end-of-life decisions were often limited to choosing for or against cardiopulmonary resuscitation. Now, the range of decisions deemed legally and ethically appropriate and desirable includes a much broader choice of decisions. These include do-not-hospitalize orders; whether to provide nutrition or hydration by enteral or intravenous routes; whether to initiate or prohibit future interventions aimed at cure (i.e., antibiotics); discontinuing potentially life-sustaining treatments, including feeding tubes and intravenous fluids, mechanical ventilation, or renal dialysis¹⁷; providing sufficient analgesia necessary to control pain, even if such analgesia were to inadvertently shorten life; and, optionally, because it is controversial, the issue of terminal sedation.^{18,19}

PROCEDURAL VS. VALUES DIRECTIVES

In lieu of written advance directives, two alternative and complementary approaches help define a patient's wishes about critical medical decisions: procedural directives and values directives. Procedural directives define which procedures or interventions should be undertaken or excluded in various situations.²⁰ The physician should attempt to determine if the patient, while still able to make decisions, had expressed a specific procedural directive. (See Communications Pitfalls section.)

Approaching decision making using values history²¹ begins with assessing the patient's values about quality of life, survival, and belief in the value of biomedicine, and then attempts to identify preferred approaches in a variety of situations that are consistent with those values.²¹ In the event that a patient has never discussed terminal care specifically, a reconstructed values history often is the only way to approximate the patient's likely preferences. Families often are able to identify comments, behaviors, and attitudes to construct a reasonable values history that can help establish an appropriate plan of care.

SUPPORTIVE VS. LIFE-MAINTAINING CARE

While family members struggle to identify specific procedural or values statements, often it is helpful to have a continuum of decisions anchored on either end with two distinct health care goals: maximal supportive care

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primarily aimed at comfort and dignity, and maximal diagnostic and therapeutic care primarily aimed at maintaining life. Most competent patients and families realize that each goal may be appropriate at certain times, and that, near the end of life, these two goals often become mutually exclusive. Framing the discussion along this continuum may help the family construct the patient's value history.

It should be noted that in situations where prognosis is uncertain or the family is unable to accept the inevitability of the patient's death, the option of a time-limited therapeutic trial, with criteria established up front for moving to supportive care, may represent a viable compromise.^{21,22}

LEGALITY

When discussing end-of-life plans with a family, physicians should know whether these decisions are legal in the states in which they practice. In nearly all legal jurisdictions, the courts support decisions in which families and physicians agree about prognosis and the patient's preferences. Some states, including Missouri and New York, require a higher burden of proof for certain substituted judgment decisions, such as discontinuing feeding tubes.^{14,15,23-25}

Communication

RAPPORT BUILDING

Any discussion should be conducted in an appropriate and comfortable setting. If the patient is unable to participate, crowding around the bed may not be the best option. If the physician is unfamiliar with members of the family, time should be spent identifying each family member's relationship to the patient. This focused introduction provides the physician an opportunity to observe family members with the patient and with each other before approaching the issues at hand.

COMMUNICATIONS PITFALLS

The question, "Do you want to have everything done for your [parent]?" should be avoided. No person wants nothing done for a loved one. Instead, reframe this question to contrast whether everything should be done for comfort or everything done for survival.

Discussions about tube feeding usually are charged with guilt that failing to provide artificial nutrition is tantamount to starving the patient to death. It often is helpful to discuss the patient's interest in food and liquids (usually diminished or absent at the end of life), medical observation that artificial nutrition often increases the patient's awareness of discomfort and

distress, and that when the patient has lost hunger and thirst without receiving artificial nutrition, the result is typically a gradual slip into a coma rather than any form of suffering.^{26,27}

Physicians should be aware of the possibility of interpreting a patient's statement out of context. In eliciting a patient's previously stated preferences, a past isolated statement made by the patient that, "I would not want to go on a respirator," may have been intended in a particular situational context (i.e., the desire to avoid permanent respirator support after a massive cerebral vascular accident). Such a statement may not have been meant to apply to all situations.

RESPONDING TO EMOTIONS

The emotional process of establishing plan-of-care decisions for a dying family member is extremely complex. Perhaps nowhere else in medicine is there a greater need for sensitive handling of feelings and emotions. Family members may not express their feelings spontaneously, especially if the physician is unknown to them, but it is almost always reasonable to expect the presence of strong emotions and to ask about the family's interest in sharing those feelings. Such inquiry clearly establishes that emotions are important, appropriate, and expected.

It is easy to misinterpret the meaning behind emotionally charged statements. Frequently, a family member will respond, "This is so upsetting." A response, "I understand," may close the door to a real understanding of the personal issues behind the feelings. A more effective response might be, "I appreciate that you are upset. For you, what's most upsetting about this situation?"

PHYSICIAN RECOMMENDATIONS

After listening and clarifying, physicians should share their opinions and recommendations. Recognizing the importance of patient autonomy and the potential abuse of power, some physicians may avoid giving specific advice. However, families facing these decisions often need the benefit of their physician's clinical judgment. The more recommendations are framed with reference to what is known about the patient's wishes, the more useful the recommendations will be. Recommendations for sequencing an end-of-life consultation appear in *Table 1*.¹⁸

The challenge of establishing a plan of care for terminally ill patients who lack decision-making capacity falls on the shoulders of the patient's physician.²⁸⁻³⁰ The physician's experience in discussing end-of-life issues with the family members of these patients can be as rewarding as it is unsettling. Patients' families usu-

TABLE 1

Recommended Steps for Discussing End-of-Life Plans of Care

1. If durable power-of-attorney or a living will is present, these documents should guide the subsequent process as much as possible.
2. If neither durable power-of-attorney nor written directive is in effect, determine who should be approached to make the decisions. Determine if any key members are absent. Try to keep those who know the patient best in the center of decision making.
3. Find a quiet place to meet where each family member can be seated comfortably.
4. Sit down, and establish rapport with each person present. What is each person's relationship with the patient? How is each person responding to the patient's present condition?
5. Clarify the difference between substituted judgment and decisions in the best interest of the patient.
6. Try to achieve a consensus about the patient's clinical situation, especially prognosis.
7. Question whether the patient has ever communicated clear procedural directives or a values history.¹⁸
 - a. If so, reinforce the principle of substituted judgment following the patient's previously stated preferences. Proceed to #9.
 - b. If no specific statements or directives had been given, try to recreate a values history at least on the issue of survival versus comfort and dignity.
8. Be an active participant. Share your interpretation of the meaning of the patient's words and behaviors. Use such statements and recommendations to support family's impressions or to provide a professional observation upon which the family can build. If your recommendation differs from the family's, let them know, and seek clarification of the differences.
9. After such a discussion and negotiation, restate or reframe the value statement that best matches the patient's expressed or implied values.
10. Discuss specific procedures and directives, as appropriate.
11. Depending on the family's substituted judgment, describe what will and will not be done. Especially if not choosing aggressive care, assure the family of the attention to patient comfort and dignity that will occur. Seek verbal confirmation of understanding and agreement.
12. Throughout the interview, there are usually a number of opportunities to respond to feelings and to support family members. Attention to the family's emotional responses is appropriate and appreciated.

Information from reference 18.

TABLE 2

Recommendations for Discussing End-of-Life Medical Decisions

<i>Recommendation</i>	<i>Comments</i>
Agree on the prognosis. ⁸	Explicitly affirm that the family's view of prognosis is similar to yours. If not, work on this.
Discuss "how to decide" before "what to decide." ¹⁴	Establish agreement to search for the decision that the patient would make if competent.
Frame the values of survival and end-of-life comfort equally. ¹⁶	At the end of life, this fundamental choice may direct care.
Discuss all choices, not just do-not-resuscitate orders.	Discuss positive and negative aspects of hospitalization, medical treatment, and nutrition and hydration. ¹⁷
Search for patient's values in words and behaviors. ²¹	Be sure to interpret isolated statements in context.
Make recommendations.	After determining the patient's values, offer recommendations explicitly linked to the patient's values and preferences.
Explore the family's feelings.	All family members are upset, but each about unique issues.

Information from references 8, 14, 16, 17, and 21.

ally are willing and virtually always appreciative of a thoughtful discussion of end-of-life plans of care.

Certain situations fall outside the usual communications process discussed here. On occasion, there is frank disagreement among family members about what should be done. When impasses develop because of long-standing intrafamily conflict or because of profound unresolved emotional difficulties, involvement of consultants (e.g., members of the hospital ethics committee or a palliative care service) may be helpful.

Many patients and families using substituted judgments will decide against high technology and high-cost interventions when quality of life is poor. Without such planning, care is often costly, uncomfortable, undignified, and ineffective. The physician's comfort with the discussions outlined in this article usually leads to a win-win situation for individual autonomy and cost-effective health care.³¹ Using available resources to provide comfort and dignity to those who are dying and have a limited quality of life usually provides better care than using technology in an unsuccessful fight for survival.³² *Table 2* lists recommendations for initiating end-of-life discussions.^{8,14,16,17,21}

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REFERENCES

- Fins JJ. Advance directives and SUPPORT. *J Am Geriatr Soc*. 1997;45:519-20.
- Blackhall LJ, Cobb J, Moskowitz MA. Discussions regarding aggressive care with critically ill patients. *J Gen Intern Med* 1989;4:399-402.
- Bedell SE, Pelle D, Maher PL, Cleary PD. Do-not-resuscitate orders for critically ill patients in the hospital. How are they used and what is their impact? *JAMA* 1986;256:233-7.
- Ventres WB, Spencer SS. Doctor-patient communication about resuscitation: "have you signed an advance directive?" *J Fam Pract* 1991;33:21-3.
- Emanuel LL, Danis M, Pearlman RA, Singer PA. Advance care planning as a process: structuring the discussions in practice. *J Am Geriatr Soc* 1995;43:440-6.
- Aitken PV Jr. Incorporating advance care planning into family practice. *Am Fam Physician* 1999;59:605-14,617-20.
- Larson DG, Tobin DR. End-of-life conversations: evolving practice and theory. *JAMA* 2000;284:1573-8.
- Balaban RB. A physician's guide to talking about end-of-life care. *J Gen Intern Med* 2000;15:195-200.
- Brody H. Medical ethics. Kansas City, Mo.: American Academy of Family Physicians, March/April 1993.
- Luce JM, Fink C. Communicating with families about withholding and withdrawal of life support. *Chest* 1992;101:1185-6.
- AGS Ethics Committee. Making treatment decisions for incapacitated older adults without advance directives. *J Am Geriatr Soc* 1996;44:986-7.
- Karlawish JH, Quill T, Meier DE. A consensus-based approach to providing palliative care to patients who lack decision-making capacity. *Ann Intern Med* 1999;130:835-40.
- Finucane TE, Denman SJ. Deciding about resuscitation in a nursing home. Theory and practice. *J Am Geriatr Soc* 1989;37:684-8.
- Emanuel EJ. A review of the ethical and legal aspects of terminating medical care. *Am J Med* 1988;84:291-301.
- Areen J. The legal status of consent obtained from families of adult patients to withhold or withdraw treatment. *JAMA* 1987;258:229-235.
- Mazur DJ, Hickman DH. Patient preferences: survival vs quality-of-life considerations. *J Gen Intern Med* 1993;8:374-7.
- Gillick MR. Rethinking the role of tube feeding in patients with advanced dementia. *N Engl J Med* 2000;342:206-10.
- Quill TE, Byock IR. Responding to intractable terminal suffering: the role of terminal sedation and voluntary refusal of food and fluids [published correction appears in *Ann Intern Med* 2000;132:1011]. *Ann Intern Med* 2000;132:408-14.
- Truog RD, Burns JP, Mitchell C, Johnson J, Robinson W. Pharmacologic paralysis and withdrawal of mechanical ventilation at the end of life. *N Engl J Med* 2000;342:508-11.
- Emanuel LL, Emanuel EJ. The medical directive. A new comprehensive advance care document. *JAMA* 1989;261:3288-93.
- Doukas DJ, McCullough LB. The values history. The evaluation of the patient's values and advance directives. *J Fam Pract* 1991;32:145-53.
- Singer PA, Martin DK, Kelner M. Quality end-of-life care: patients' perspectives. *JAMA* 1999;281:163-8.
- Lo B, Rouse F, Dornbrand L. Family decision making on trial. Who decides for incompetent patients? *N Engl J Med* 1990;322:1228-32.
- Luce JM, Alpers A. End-of-life care: what do the American courts say? *Crit Care Med* 2001;29(2 suppl):N40-5.
- Diamond EL, Jernigan JA, Moseley RA, Messina V, McKeown RA. Decision-making ability and advance directive preferences in nursing home patients and proxies. *Gerontologist* 1989;29:622-6.
- Ganzini L, Goy ER, Miller LL, Harvath TA, Jackson A, Delorit MA. Nurses' experiences with hospice patients who refuse food and fluids to hasten death. *N Engl J Med* 2003;349:359-65.
- Li I. Feeding tubes in patients with severe dementia. *Am Fam Physician* 2002;65:1605-10.
- Paris BE, Carrion VG, Meditch JS Jr, Capello CF, Mulvihill MN. Roadblocks to do-not-resuscitate orders. A study in policy implementation. *Arch Intern Med* 1993;153:1689-95.
- Davidson KW, Hackler C, Caradine DR, McCord RS. Physicians' attitudes on advance directives. *JAMA* 1989;262:2415-9.
- Ventres W, Nichter M, Reed R, Frankel R. Do-not-resuscitate discussions: a qualitative analysis. *Fam Pract Res J* 1992;12:157-69.
- Singer PA, Lowy FH. Rationing, patient preferences, and cost of care at the end of life. *Arch Intern Med* 1992;152:478-80.
- Schulz R, Mendelsohn AB, Haley WE, Mahoney D, Allen RS, Zhang S, et al. End-of-life care and the effects of bereavement on family caregivers of persons with dementia. *N Engl J Med* 2003;349:1936-42.