

EPEC

Education for Physicians on End-of-life Care

Participant's Handbook

Module 1

Advance Care Planning

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Abstract

Advance care planning is the process of planning for future medical care, particularly for the event when the patient is unable to make his or her own decisions. It should be a routine part of standard medical care and, when possible, conducted with the proxy decision maker present. It is helpful to think of the process as a stepwise approach. The steps include the appropriate introduction of the topic, structured discussions covering potential scenarios, documentation of preferences, periodic review and update of the directives, and application of the wishes when needed. The steps can then be flexibly integrated into routine clinical encounters by the physician and other members of the health care team. The process fosters personal resolution for the patient, preparedness for the proxy, and effective teamwork for the professionals. The process also has pitfalls to be aware of.

Key words

advance care planning, advance directive, advisory document, durable power of attorney for health care, honoring patient wishes, living will, personal preparation, pitfalls, proxy, statutory document, structured discussion, worksheet

Objectives

The objectives of this module are to:

- define advance care planning and explain its importance
- describe the steps of the advance care planning process
- describe the role of patient, proxy, physician, and others
- distinguish between statutory and advisory documents
- identify pitfalls and limitations in advance care planning
- be able to utilize planning to help the patient put affairs in order

Clinical case on trigger tape

The patient is Keith Cunningham, a 55-year-old computer salesperson who is diabetic with mild hypertension, but otherwise in good health. Mr Cunningham has come in for a routine physical exam. In reviewing the chart, the physician notices that advance directives have not been addressed.

Introduction

What is advance care planning?

Advance care planning is a process, not an event. It is the process of planning for future medical care in the event that the patient is unable to make his or her own decisions. During this process patients explore, discuss, articulate, and document their preferences.

The process helps patients identify and clarify their personal values and goals about health and medical treatment. They identify the care they would like, or not like, to receive in various situations. Patients also determine whom they would like to make health care decisions on their behalf in the event they cannot make decisions for themselves.

Ideally, advanced care planning is a process of structured discussion and documentation woven into the regular process of care that is reviewed and updated on a regular basis. It is designed to ensure that a patient's wishes will be respected in the event that the patient is unable to participate in decision making. In the case of a pediatric patient, it is designed to ensure that the patient's parents are provided with an understandable discussion of the child's prognosis, and of the treatment options, should the child's condition deteriorate to a terminal state. The sense of control and peace of mind that this process fosters in the patient and the reduction in anxiety of proxy decision makers are important benefits.

Advance care planning is important for physicians for many reasons. Patients have a right to participate in the planning of their health care. Physicians have a legal and professional responsibility to assure this, even if the patient loses the capacity to make decisions. The process of determining those preferences for treatment builds trust and a sense of teamwork between the patient, the proxy, and the physician in several ways. The invitation to discuss future care permits the patient (or the parents if the patient is a child) to understand his or her own values, goals, and preferences that govern his or her life. The physician and proxy learn about those preferences and needs. The process helps to relieve anxieties and fears on both sides because a spirit of frankness and openness is fostered. Advance care planning is preventive medicine because it avoids future confusion and conflict.

The model for advance care planning can be applied to other decision-making processes as patients plan for the end of their lives (eg, planning for bequests, autopsy, burial/cremation, funeral/memorial services, guardianship, choices of caregivers and settings for care).

Involvement of others

The physician plays an important role in initiating and guiding advance care planning. He or she needs to be involved in some, but not all, stages of advance care planning in order to understand the patient and establish a trustworthy shared decision-making process. Recent studies suggest that patients prefer discussing these issues with their family members. However, as the physician will be responsible for the actual medical orders, sufficient involvement is necessary for the physician to feel comfortable that he or she can pursue the goals and priorities for care that the patient wants.

Many physicians are concerned that advance care planning is too idealistic or time-intensive to include it in their busy practice. The purpose of this module is to provide a framework for the routine and practical inclusion of the process into practice. The patient, proxy, and family can do most of the work without the physician if they are given a

worksheet and background materials. For purposes of reimbursement, the time that the physician takes to counsel and provide information about advance care planning can be incorporated into the coding of complexity of the encounter. Please refer to the section entitled “Reimbursement mechanisms and procedure/diagnosis coding for physician services in palliative care” in the Appendix of the EPEC materials.

Some physicians choose to have other members of the health care team assist them with advance care planning (eg, a nurse, physician assistant, or social worker). Once the patient’s ideas have been gathered, the physician can focus on the core discussions in direct meetings with the patient, proxy, and family. Preparatory work will permit these discussions to be to the point and effective. Once the core discussion has taken place, invite the patient to reflect on things and then return at a subsequent visit with decisions to review.

There are legitimate cultural, ethnic, and age related differences in approaches to medical decision making and advance care planning. However, generalizations should not be used to rationalize the omission of this topic for an individual patient. Pediatric patients and their parents can benefit from the advance care planning process, too. Determine how a patient and family want medical information to be shared and medical decision making handled early in the therapeutic relationship. See Module 2: Breaking Bad News for a discussion of how to do this.

Terms used in advance care planning can be confusing. *Advance directives* are prior directives by the patient for his or her health care. Advance directives fall into two categories, those that have to do with instructions for medical care and those that have to do with designating a proxy for the patient. *Instructional directives* for care can be recorded in a number of types of documents. A *living will* is usually a simple statement asking for no heroic care in case of poor prognosis. A personal letter may also be used. A *values history* is a statement of values regarding health care in life-threatening illness situations. A *medical directive* is a set of instructions based on likely scenarios of illness, goals for care, and specific treatments, combined with a general values statement. It is also combined with a proxy designation section. A person who is empowered to make decisions in the place of the patient is sometimes termed a *health care proxy* or a *durable power of attorney for health care*. Laws and policies regarding advance care planning are summarized in the Appendix of this module and are presented in more detail in Plenary 2: Legal Issues in End-of-life Care.

5 steps for successful advance care planning

Step 1: Introduce the topic

Research shows that most patients believe that it is the physician’s responsibility to start advance care planning and will wait for the physician’s initiative. Advance care planning is most easily accomplished during stable health, since changes often require a period for adjustment before the patient will have stable goals again.

In the face of life-threatening illness or other significant change in health status, advance care planning becomes even more necessary. Try to find a time when there is as much stability and adjustment to the new illness circumstances as possible.

Sometimes the most difficult part of the advance care planning process is the introduction of the topic. Physicians often have a number of concerns that make them reluctant to do so. Some may be concerned that the subject of advance care planning will frighten the patient or send the “wrong message.” Others may be uncertain about the most effective approach to use. In fact, most patients welcome the opportunity to discuss their preferences with their physician, and physicians who routinely engage in the process find it helpful and not too time-consuming.

While some patients will be more likely to need advance care planning than others, healthy people who experience an unexpected illness, such as major trauma, can suddenly be the patients most in need of advance directives. Whenever possible, routinely initiate the advance care planning process with every adult patient in your practice, regardless of age or current state of health. An outpatient office or other nonthreatening setting is ideal.

For pediatric patients with a chronic illness, the optimal timing of advance care planning will vary. At a minimum, the discussion should take place at the time of relapse of disease, or at the time of significant complications, before the child is in a state of crisis.

When introducing the topic, inquire how familiar the patient is with advance care planning. Some patients may already have advance directives in the form of a living will or durable power of attorney for health care. If this is the case, review the documents and amend them if appropriate. An advisory medical directive can be used to amend existing statutory documents. (See step 3.)

Before beginning the process, be prepared to explain the goals and the process that you recommend using. You may have literature that you would like the patient to read. If you are using a validated worksheet, give it to the patient to look over before the next discussion. Explain the roles of other family members, or a proxy. If appropriate, introduce other members of the health care team who will be involved in the process.

While most patients will welcome the opportunity to discuss these matters, be aware of the patient’s comfort level during the introduction of the topic. If a patient (or parent if the patient is a child) does not seem comfortable talking with you, be supportive and provide information, but do not force the conversation. It may happen later when the patient is ready.

As patients frequently wish to minimize the decision-making burden for family, suggest that the patient involve family members, friends, and even members of the community to explore how to best manage potential burdens. Ask the patient to identify a possible proxy decision maker who might act on his or her behalf, to be involved in subsequent conversations. The best proxy decision maker is not always a family member or significant other. Sometimes the decisions are too difficult for people close to the patient, who may be overly influenced by their attachment or by burdens of care. Whether close or not

so close, the proxy should be someone whom the patient trusts and who would be willing and able to represent the patient's wishes. Encourage the patient to bring that person, or persons, to the next meeting and book a time to follow-up.

Step 2: Engage in structured discussions

A critical success factor for advance care planning is the ability to structure discussions with the patient that both convey the information patients need and elicit relevant preferences to determine their advance directives. A script is provided at the end of this module in the Appendix that you may wish to use or modify. It may help you to think about ways to conduct the discussion.

To prevent any misunderstanding, remind the patient that it is the goal of advance care planning to plan the potential loss of his or her capacity to make decisions, either temporarily or permanently. Convey the physician's and health care team's commitment to follow the patient's wishes, desire to protect the patient from unwanted treatment or undertreatment, and desire to help plan for any caretaking needs of the patient's family or significant others.

Role of the proxy

Involve the potential proxy decision maker in the discussions and planning so that he or she can have a thorough and explicit understanding of the patient's wishes. Usually, the appropriate role for the proxy during the initial discussions is to listen, perhaps to take notes, and to ask questions for clarification. A joint meeting between the patient, physician, and proxy to ensure common understanding can be invaluable if the proxy and physician are later called on to collaborate in decision making.

As part of the advance care planning process, the patient should specify the role he or she would like the proxy to assume if the patient is incapacitated. Proxies may try to implement specific treatment choices, or they may try to decide according to the patient's best interests, or they may decide by taking into consideration the interests of all parties that the patient cares about in a form of substituted judgment. While these possibilities often coincide, they may not, and it can be very helpful for the patient to decide which standard is most important to him or her.

In all cases, the proxy will need to work with the physician and, in general, should have the same participation in decisions that the patient would have had. Most commonly, the proxy uses a blend of standards — his/her own best judgment based on the situation and what he/she knows about the patient's wishes. This allows for unexpected factors that could not be anticipated during the advance care planning process.

Patient and proxy education

At the core of advance care planning is the empowerment and preparedness of the patient and proxy. Both usually require some education, time for reflection, and discussion. In

order to make informed choices, the patient must understand the meaning of the various clinical scenarios under discussion, as well as the benefits and drawbacks of the various treatment options. The discussion should provide insight into the types of clinical scenarios that might arise and the types of decisions that proxies most commonly face.

Define key medical terms using words the patient and proxy can understand. Explain the benefits and burdens of various treatment options (eg, life support on a ventilator may only need to be used for a short time if the underlying problem is reversible). Remind them that any intervention can be refused or stopped if it is not meeting overall treatment goals (see Module 11: Withholding, Withdrawing Therapy). Because recovery cannot always be predicted, help patients to consider situations involving uncertainty, incomplete recovery, or even death.

Elicit the patient's values and goals

Develop an understanding of the patient's values and goals related to health and illness (see Module 7: Goals of Care). For pediatric patients, involve them to the level they are comfortable with and work with the parents/guardian. There are a number of ways to facilitate this part of the discussion. Ask about past experiences, either the patient's own or those of other people the patient knows. Describe possible scenarios and ask the patient what he or she would want in such a situation.

As a range of clinical situations is reviewed with the patient, it will be possible to get a sense of where thresholds exist for withdrawal or withholding of care. Help the patient to articulate his/her own general principles, values, and goals for care in given situations and specific treatment wishes. Consider asking the patient if he or she wants to write down in a letter to the physician how such things should be handled.

Some patients and proxies will have an emotional response to the material. Respond to the emotional reactions. Responding to emotions in the context of an interview is discussed in Module 2: Communicating Bad News.

Use a validated advisory document

To guide the discussion and capture patient preferences, consider using a worksheet or other carefully developed and studied tool, such as a linear or interactive videotape or a software program. Many people find that, by using a worksheet, the discussion with the patient readily identifies the patient's values and attitudes regarding health and medical care across a range of medical situations, possible goals, and treatment choices. By going through various scenarios and options, the patient's personal threshold for use/nonuse of interventions can become clearer. Proxy decision makers can be identified and their roles defined.

Ensure that the worksheet includes a range of potential scenarios that patients should consider. It should elicit the patient's values and goals related to health and medical care in general terms and should include the most common life-saving interventions. If a pa-

tient already has a life-threatening condition, the conversation may be more focused on specific scenarios and treatment issues. For example, a patient with end-stage cardiomyopathy really needs to consider the issues of cardiopulmonary resuscitation (CPR) and the role of intensive care units. The patient with end-stage renal disease must consider dialysis. The patient with advanced AIDS needs to consider dementia and respiratory failure.

A number of validated worksheets are available to choose from (see Resources and the Appendix). They provide a consistent approach, are easy to use, and reduce the chance that important information will be left out or framed in a biased way; the preferences they elicit tend to be reliable and durable reflections of the patient's wishes. Once they are complete, worksheets can serve as a resource that the patient, proxy, and family members take home. They may also be able to serve as a formal advisory document.

Step 3: Document patient preferences

Formalize the directives

Once the patient has come to some decisions, it is crucial for the physician to review the advance directives with the patient and proxy. Check for, and help to correct, any inconsistencies and misunderstandings. Make sure that the directives provide the type of information needed to make clinical decisions.

After a final review is complete, ask the patient to confirm his or her wishes by signing the directives. Although any statement of a patient's wishes, written or verbal, can be considered an advance directive and should be respected by physicians, a formal written document signed by the patient can avoid ambiguity.

Enter directives into the medical record

Once the directives have been reviewed and accepted, the physician must formally document them in the patient's medical record. When a validated worksheet has been used to structure the planning discussion, the completed, finalized, and signed worksheet can itself be used as the entry in the medical record.

In the absence of a validated worksheet, the physician should describe the patient's wishes in a written document and ask the patient to review and amend it as appropriate. Once everyone is satisfied, have the patient sign the document and enter it into his or her medical record. It is also useful for the physician and proxy to sign the advance directive and provide their location information. This offers reassurance to the patient and helps to ensure the physician's and proxy's involvement in eventual decision making.

Recommend statutory documents

For added protection, patients should be encouraged to complete one or more statutory documents (eg, living will or durable power of attorney for health care) that comply with state statutes. Physicians should familiarize themselves with the specific advance direc-

tive statutory requirements of their state. They can do this by checking with their hospital's legal counsel, their state attorney general's office, or their local medical society.

Distribute the directives

It is important to have these records wherever the patient may receive care. Place them into a central repository (such as a hospital or a regional or national center). Provide copies to the patient, proxy decision maker, family members, and all health care providers as appropriate. Use wallet cards to help ensure that the information is available when it is needed.

Change the plan of care

Once preferences have been documented, the physician may need to change the plan of care and put certain things in place to ensure that the patient's wishes can be followed. For patients who may wish to remain at home and never be taken to an emergency department or be hospitalized again, appropriate alternative arrangements, including referral to a home hospice agency, provision of appropriate medications, and instructions detailing how to handle symptoms and crises may possibly be needed. Practical suggestions may be helpful. Consider posting telephone numbers by the home telephone to call in an emergency (eg, the hospice nurse on call), or numbers not to call (eg, 911).

Step 4: Review and update the directive

It is important to revisit the subject of advance care planning on a periodic basis to review the patient's preferences and update the documents. Major life events such as illness, marriage, the birth of a child, or the death of a loved one may affect a person's attitude toward their health care and/or end-of-life care.

Any changes in preferences warrant discussion to allow the patient to reassess and to ensure that the physician and proxy decision maker fully understand the new wishes.

Changes in preferences should be documented and existing documents should be updated and shared appropriately.

Step 5: Apply directives to actual circumstances

When patients become incapacitated, the application of prior wishes to real circumstances can be challenging. The following guidelines may be helpful to ensure that a patient's advance directives are followed as closely as possible.

Most advance directives go into effect when the patient is no longer able to direct his or her own medical care. Learn to recognize when a patient becomes incapable of making decisions. While situations where the patient is unresponsive are obvious, if the patient

has some ability to respond, the physician must first determine his or her capacity to make decisions (see Module 7: Goals of Care).

Never assume an advance directive's content without actually reading the document. Do not take for granted that patients who have living wills want treatment withheld. Some people indicate within their living will that they want all full measures taken to prolong their life.

Advance directives should be interpreted in view of the clinical facts of the case. Validated documents are likely to be more useful than short statements or statutory documents. No matter how thorough they are, advance directives cannot anticipate all possible circumstances. The proxy and the physician may need to extrapolate from the scenarios described in the advance directive to the current situation, and make an educated guess as to what the patient would want if he or she were able to speak for himself or herself.

Whenever significant interpretation is necessary, the physician should consult the patient's proxy. Sometimes the physician and/or proxy may believe that a patient would have indeed wanted something other than what is reflected by a strict reading of the advance directive. In this case, they should work together to reach consensus.

Certain patterns of decisions have high predictability and follow logically. For instance, a declination of less invasive interventions has been shown to predict declinations of more invasive interventions. Acceptance of more invasive interventions predicts acceptance of less invasive interventions. If a patient has indicated that he or she would like intervention in a poor-prognosis scenario, there is a high probability that the patient would also accept intervention in a better-prognosis situation. Likewise, if the patient has indicated he or she would decline intervention in a better-prognosis scenario, there is a high probability he or she would also decline if the prognosis were poor.

If disagreements cannot be resolved, assistance should be sought from an ethics consultant or committee.

Common pitfalls of advance care planning

Anticipating and avoiding the common pitfalls is essential to a successful advance care planning process. There are several.

Failure to plan: Do not avoid advance care planning. Too often, situations occur and decisions are made without the benefit of advance care planning. Be proactive. It is easy to forget the central role of the patient, and easy to forget the importance of the proxy. Involve both early and often.

Proxy not present for discussions: Do not leave the proxy decision maker(s) out of the initial discussions with the patient.

Unclear patient preferences: Vague statements can be dangerously misleading. Be sure to clarify patient preferences if they do not seem clear to you or to the proxy. For in-

stance, patients who make statements such as “I never want to be kept alive on a machine” should be asked to clarify whether their wishes would change if their condition were readily reversible, or if their prognosis were unclear.

Discussion focused too narrowly: Avoid isolated do-not-resuscitate (DNR) discussions; they often create chaotic emotions and thoughts in patients who have to imagine imminent death to make the decision. A DNR discussion is usually an indication that other palliative goals and measures should be considered in the context of a range of scenarios.

Communicative patients are ignored: Sometimes people assume that what a patient wants in the present is what he or she indicated for future possible scenarios. As long as the patient is competent, talk to him or her. An impaired patient may still be able to express wishes at some level. In such cases, both the advance directive and tangible evidence of the patient’s current wishes should be taken into account.

Always read advance directives: Sometimes physicians assume that they know what is stated in an advance directive. This is a mistake. Advance directives can be for aggressive intervention, comfort care, or a wide range of specific views and must be read and understood.

Complementary application of the model for advance care planning

Preparation for the last hours of life

Planning other issues that face patients at the end of their lives is critical if their needs and expectations are to be respected by health care professionals and family members who will survive them. While it would be ideal if all patients and families prepared for death well in advance of the final hours of their lives, most patients with advanced illnesses and their families have neither discussed nor prepared for their death.

As patients approach the last hours of their lives, they have a last chance to finish their business, create final memories, give final gifts, and say their good-byes. If appropriately assisted, considerable planning can be accomplished around many of these issues.

The 5-step model for eliciting, documenting, and following advance directives can be used to guide these decision-making processes and document patient choices. As these important tasks are generally more than individual physicians can handle, other members of the interdisciplinary team can help patients and families complete their business and get their affairs in order.

In preparing for death, it is important to understand the perspective and wishes of all who are present: the patient, the family, and the caregivers. Personal expectations, agendas, fears, phobias, and acceptable setting(s) for care need to be clear, since any one person may alter the course of care unexpectedly and may interfere with the patient’s wishes if such are not clearly known. Personal, cultural, and religious values, beliefs, and practices

need to be anticipated and respected, as missed rites/rituals or errors made by unknowing caregivers may have grievous consequences in the eyes of the patient or family members. Identification and acknowledgment that some family members have a need to give care and others don't will help to allow each to participate as closely as makes him/her comfortable.

Advance practical planning

Many patients will choose to get their financial and legal affairs in order, give gifts and plan for bequests, organ donation, autopsy, burial/cremation, their funeral/memorial services, and guardianship of their children as they finish their business. Some patients will even want to give family members permission to build new lives after they die.

Choice of caregivers

The choice of caregivers for each patient is crucial as vulnerability increases. Patients may or may not want family members to care for them. Family members may or may not be able to assume responsibilities for caring and should ideally have the opportunity to be family first and caregivers only if both they and the patient agree to the role. All caregivers need to have the opportunity to change their role if they feel the stress is too much, or they are not getting enough chance to finish their personal business with the patient.

Choice of setting

The choice of the care setting for the last hours of a person's life should be as acceptable as possible to the patient, the family, and all caregivers. Each setting will carry benefits and burdens. Whatever the choice, the setting should permit family members to remain with the patient as much as they want, and provide them with opportunities for privacy and intimacy. While dying at home may be the wish of many patients, such a choice may expose family members to undue burden or compromise their careers, their personal economic resources, or their health. If the number of able caregivers and personal resources is limited or if family members are afraid of ghosts and would not be able to live on in their home afterward, care and death in the home may not be the best choice. An alternate inpatient setting may be a hospice or palliative care facility, a skilled nursing facility, or even an acute care facility. Depending on the resources that are locally available and whether the staff is skilled in this kind of care, these alternative settings may lead to a far better outcome.

Summary

Advance care planning should be a routine part of standard medical care that is integrated into clinical encounters by the physician and other members of the health care team. Formally, it can be thought of as a stepwise approach, to include the appropriate intro-

duction of the topic, structured discussions covering potential scenarios, documentation of preferences, periodic review and update of the directives, and application of the patient's wishes when needed. Less formally, the process fosters personal resolution for the patient, preparedness for the proxy, and effective teamwork for the professionals.

A number of critical factors contribute to a successful process and outcome: physician guidance and participation, family/proxy participation, and use of a worksheet or structured materials to foster discussion and documentation.

The process also has pitfalls to be aware of. Vague or misleading statements of wishes can be hazardous; failure to involve the proxy risks discord around decisions; premature activation of the directive when the patient is still competent fails to honor the patient's real-time autonomy; and assumptions about wishes in advance directives being for no-intervention may not be accurate.

Key take-home points

1. Every person has a very personal sense of how he or she would like to live and die that will be based on personal, cultural, and religious values, beliefs, and preferences.
2. Every person has the right to participate in the planning of his or her health care.
3. Advance care planning is a process to help a patient plan for the potential loss of capacity to make decisions about his or her medical care, either temporarily or permanently.

Step 1: Introduce the topic

4. Most patients welcome the opportunity to discuss their preferences with their physician. As anyone may suddenly and unexpectedly become ill and incapacitated, routinely initiate the advance care planning process with every adult patient in your practice, regardless of age or current state of health.

Step 2: Engage in structured discussions

5. Communicate information using the principles for information sharing outlined in Module 2.
6. Involve the potential proxy decision maker in the discussions and planning so that he or she can have a thorough and explicit understanding of the patient's wishes.
7. Develop an understanding of the patient's values and goals related to health and illness.
8. Consider using a worksheet to guide discussions. Patients/families/proxies can complete them at home after they have been introduced.
9. Consider enlisting the assistance of one or more members of the health care team to help the patient with his or her advance care planning.

Step 3: Document patient preferences

10. Once the patient has completed his or her initial planning, the attending physician should sit down with at least the patient and proxy to review the advance directives and ensure that there are no inconsistencies.
11. Enter directives and any related orders into the medical record.
12. Ensure that relevant health care providers know of the directives.

Step 4: Review and update the directive

13. Revisit the subject of advance care planning on a periodic basis, particularly with major life or health changes.

Step 5: Apply prior directives to actual circumstances

14. Most advance directives go into effect when the patient is no longer able to direct his or her own medical care.
15. Capacity for decision making is different from global abilities to handle one's affairs.
16. Do not presume that patients who are very ill lack ability to make decisions.
17. Know who the "default" proxy decision maker will be if the patient has not designated one.

Complementary application of the model

18. The 5-step model for eliciting, documenting, and following advance directives can be used to guide other decision-making processes, such as gift giving and planning for care at the end of life, and to document patient choices.

Pearls

1. Complete you own advance care planning.
2. Ask proxies if they are able and willing to fulfill the role.
3. Identify a patient's personal threshold for life-sustaining intervention.
4. Have validated worksheets available in the office.

Potential pitfalls

1. Doing something to someone that he or she does not want.
2. Never introducing advance care planning.
3. Omitting the proxy from discussions between patient and physician.
4. Discussing too few possible clinical situations and treatment choices.

5. Avoiding advance care planning because the task seems too onerous.
6. Not informing loved ones/family of the patient's preferences.
7. Not knowing the patient's preferences.
8. Excluding compromised patients from decisions who retain decision-making capacity.
9. Assuming the content of an advance directive without reading it.
10. Letting health care providers' own values and choices interfere with the patient's expressed preferences.

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Appendix

Advance care planning: the law and policy

Common law, federal and state legislation, and official policies of medical organizations support advance care planning.

- **US Supreme Court, 1990:** Upheld the patient's right to self-determination, establishing that the right applies even to patients who are no longer able to direct their own health care, and that decisions for incompetent patients should be based on their previously stated wishes.
- **Federal law, 1991:** The Patient Self-determination Act requires that patients be informed of their rights to accept or refuse medical treatment and to specify in advance the care they would like to receive should they become incapacitated.
- **State law:** The patient's right to specify wishes in advance has been codified into statute in all 50 states. Statutory documents recognized by law include the *living will* and the *durable power of attorney for health care*.
- **Statutory documents** are those that are specifically described and defined in state statute. These documents are to help protect physicians who honor a patient's wishes. When such documents are used, rights, obligations, and protections are clearly defined. Nonstatutory documents or *advisory documents* are legal. They are based on common law rights. They are supposed to accurately reflect a patient's wishes. In some states or settings, an advisory document is enough; in others, a statutory form should be used as well. Especially in states where a legal guardian may be necessary if there is no statutory power of attorney for health care, one is recommended.
- **Professional policy:** The AMA's Council on Ethical and Judicial Affairs identified advance care planning as an essential component of standard medical care in 1997. It called for physicians to conduct advance care planning discussions on a routine basis using advisory documents as an adjunct to statutory documents, such as the living will and the durable power of attorney for health care. The American College of Physicians' Ethics Manual, 4th edition, 1998, also supports advance care planning.

Advance care planning discussion scripts

Mrs Jones has come in for a routine examination:

“Mrs Jones, I’d like to talk with you about something I try to discuss with all of my patients. It’s called advance care planning. In fact, I feel that this is such an important topic that I have done this myself, with my own physician. Are you familiar with advance care planning?...”

“Have you thought about the type of medical care you would like to have if you ever became too sick to speak for yourself? That is the purpose of advance care planning, to ensure that you are cared for the way you would want to be, even in times when communication may be impossible....”

“There is no change in your health that we have not already discussed. I am bringing this up now because it is prudent for everyone, no matter what their age or state of health, to plan for the future....”

“Advance care planning will help both of us to understand your values and goals for health care if you were to become critically ill. Eventually we may put your choices into a written document that I would make part of your patient record. We call this document an advance directive, and it would only be used if you were to lose the capacity to make decisions on your own, either temporarily or permanently....”

“Would you like to talk further about the kind of care you would want to have if you were no longer able to express your own wishes?”

“I also like to ask my patients if they have someone that they would like to identify to act on their behalf in the event that they are unable to express their own wishes. This person could be a relative or a friend. Is there someone whom you would want to be part of our discussion and whom you might want to have act on your behalf?...”

“Here is a copy of the form that I would like to use to structure our conversation. We will talk about it in more depth the next time we meet. Please think about it, talk with your family, and write down any questions you have. Also, next time please bring anyone with you whom you want to include in our discussion....”

Next visit:

Ask questions about specific scenarios. Start by asking about a persistent vegetative state.

“Mrs Jones, I suggest we start by considering a few examples as a way of getting to know your thinking. I will use examples that I use for everyone. Let’s try to imagine several circumstances. We will go through 4 and then perhaps another 1 or 2. First, imagine you were in a coma with no awareness. Assume there was a slight chance that you might wake up and be yourself again, but it was not likely. Some people would want us to withdraw treatment and let them die, others would want us to attempt everything possible, and

yet others would want us to try to restore health, but stop treatment and allow death if it were not working. What do you think you would want under these circumstances?”

Then ask Mrs Jones similar questions about 3 other scenarios:

- onset of coma from which there is a chance of recovery, but with significant disability
- onset of dementia when there is already an advanced life-threatening illness
- onset of dementia with no other life-threatening diagnosis

If she is already experiencing a significant illness, ask Mrs Jones questions specific to her current illness:

“We should also consider the situations that your particular illness can cause; that way you can be confident we will do what you want. For sure, all people are different and you may never face these circumstances. Nevertheless, let’s imagine . . .”

“People sometimes think about circumstances they have seen or heard about. Some may seem worse than death. Do you ever think about such circumstances?”

Finally, ask Mrs Jones about how she would like to handle a sudden critical illness that is life threatening.

“Well, we’ve gone through several scenarios now. It seems to me that you feel particularly strongly about Indeed, you move from wanting intervention to wanting to be allowed to die in peace at the point when Do I speak for you correctly if I say that your personal threshold for deciding to let go is . . . ?”

“I think you have given a good picture of particular decisions you would want. Can you also say something about the values or beliefs that you hold? Understanding your more general views can be an important part of getting specific decisions right.”

Next visit:

“Mrs Jones, have you and [your proxy/family member] had a chance to continue the discussion we started 2 weeks ago? I see you have a completed statement now. Let’s review your preferences.”

“I am glad we went through this planning process together. I have a much better idea of what matters to you than I did before, and that will help me to be a good physician for you — in general, as well as in case of serious illness.”

“If you feel ready to, we can write down your preferences, and all 3 of us can sign this document and make it official. Then we will put it into your medical record and give you copies to take home.”

Two years later:

“Mrs Jones, 2 years have gone by since we completed your advance care plans, and in that time a lot has happened. People sometimes change their wishes, so let’s review the wishes you wrote down two years ago.”

“Your choices have changed on a couple of your earlier decisions when we reviewed your statement, even though we have discussed the issues quite a lot. You have already said that you want [proxy/family member] to be your proxy. Would you prefer to give these few decisions over to him/her to decide according to what he/she thinks would be in your best interests?”

“For the remaining decisions, about which you are clear and firm, would you like [proxy/family member] to stick closely to them, or would you prefer to give him/her room to make changes if he/she thinks your best interests would be better served by a different decision?”

Advance care planning exercise

This is an exercise to help physicians, and other health providers, learn about advance care planning. It is written essentially as a script to be followed. The educational method is interactive rather than didactic.

It is helpful to be able to say to patients and families that you have done your own advance care planning as a matter of routine care. It is also helpful to have experienced the process of trying to imagine being in states of serious illness and mental incapacity.

First scenario

We will start by considering a scenario in which you have an advanced illness with a very poor prognosis (less than 3 months if the disease follows its usual course). You are in the hospital in a coma with a poor likelihood of recovery when you develop a small bowel obstruction.

First, consider what you would want to be the *goals* of your care in this circumstance. Would you want (a) all possible intervention to prolong life, (b) full intervention, but with early reassessment, (c) interventions that may help but that are not too invasive, or (d) noninvasive comfort care only? [*Pause briefly.*]

Now, consider what treatments you would want. Would you want major surgery? [*Pause briefly.*] How about an intermediate option with a nasogastric tube, and no intake by mouth? [*Pause briefly.*] How about only intravenous antibiotics? [*Pause briefly.*] What about only comfort measures with analgesics and sedatives?

Let's look at what goals you selected. How many of you selected all possible interventions to prolong life? [*You may want to list this on the left-hand side of a flip chart or overhead projector. Count hands and record the number.*] How many selected full interventions, but with early reassessment? [*Count hands and record the number.*] How many chose interventions that might help but are not too invasive? [*Count hands and record the number.*] How many chose noninvasive comfort care only? [*Count hands and record the number.*]

Let's look at what treatment options you selected. How many wanted major surgery? [*Count hands and record the number on the right-hand side of the flip chart or overhead projector opposite the corresponding goal.*] How many wanted intermediate interventions with an NG tube? [*Count hands and record the number.*] How many wanted antibiotics? [*Count hands and record the number.*] How many chose noninvasive comfort care only? [*Count hands and record the number.*]

Notice how many of you declined all interventions and wanted only comfort measures. Some of you wanted some noninvasive or minimally invasive measures. Also, notice the inconsistencies. When faced with specific choices, some of you changed to a different "level" as related to overall goals. If we were to move to a scenario of rosier prognosis, we would still be likely to find a range of choices within the group. Many of you would change your choices.

This process leads to an opportunity to think about your own internal inconsistencies, how you might value various options, and how you would set limits. Further, it helps you to be specific about your relationship to death and dying.

Many of the questions in your mind are questions that patients will have. Many are those that only people with advanced education ask. In fact, lawyers and physicians tend to be either the fastest or the slowest to complete these types of exercises. Most people, regardless of educational experience, find these exercises helpful and doable.

Second scenario

Now, consider a scenario in which you have a mild chronic condition. It affects your day-to-day living to a modest degree. You now contract a life-threatening but potentially reversible condition such as *Staphylococcus aureus* pneumonia. You are barely conscious and cannot make decisions for yourself. Let's go through the same exercise. First, let's discuss goals. Would you want (a) all possible intervention to prolong life, (b) intervention, but with early reassessment, (c) interventions that may help but that are not too invasive, or (d) noninvasive comfort care only? [*Pause briefly.*]

Now, consider what treatments you would want. Would you want care in an intensive care unit, including pressors and intubation? [*Pause briefly.*] Would you want a more intermediate intervention, such as multiple intravenous antibiotics and low-dose pressors but no transfer to an intensive care unit and no intubation? [*Pause briefly.*]

Now consider a barely invasive intervention— would you want IV antibiotics but a limit on the degree of laboratory testing? [*Pause briefly.*] Would you want only comfort care with analgesics and sedatives? [*Pause briefly.*]

Let's look at what you selected now. How many of you selected all possible interventions to prolong life? [*You may want to list this on a flip chart or overhead projector on the left hand side, as before. Count hands and record the number.*] How many selected intervention, but with early reassessment? [*Count hands and record the number.*] How many

chose interventions that might help but not too invasive? [*Count hands and record the number.*] How many chose noninvasive comfort care only? [*Count hands and record the number.*]

Let's look at what treatment options you selected. How many chose all measures to prolong life? [*Count hands and record the number on the right-hand side of the flip chart or overhead projector opposite the corresponding goal.*] How many wanted intermediate interventions with IV antibiotics, but no ICU care? [*Count hands and record the number.*] How many wanted only IV antibiotics? [*Count hands and record the number.*] How many chose noninvasive comfort care only? [*Count hands and record the number.*]

Notice the changes. Most of you wanted interventions that were much more “aggressive.” Contrast your answers to this scenario with the first. Do you have a sense of where your threshold for intervention lies relative to prognosis and disability? Some of you could now move to other scenarios and treatments that would more clearly define your personal threshold for intervention. For many people, it is enough to define where the threshold is, without resolved detailed decisions at the threshold. Often this is where physician recommendation plays a stronger role and proxy discretion comes in. Many patients are content with this.

Notice how most of you selected intervention choices that were consistent with your general goal. This is usually the case. However, some of you chose treatments that didn't quite correspond with the overall goal. Research shows that trying to predict intervention choices from stated general goals (such as those in a living will) is weaker than extrapolating from specific preferences. While identifying goals provides a reality check and organizes our thinking, this is not a substitute for considering specific examples.

Most people, after weighing other scenarios and having fully completed an advance care planning worksheet, will feel that their views are well articulated. Some proportion of patients, however, will feel that there is something more that needs to be said. Invite them to give you a statement in their own words, such as in a letter. Ask them to consider other matters, such as whether the patient wants to die at home, or whether autopsy and/or organ donation is desired. Invite the formal proxy to be designated. If more than one proxy is desired, invite the patient to give some sense of order of authority in cases of disagreement.

Appendix: reprinted documents

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