



The Health Care Decision-Making Process Framework

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Introduction

Many physicians are aware of the evolution of interest and thinking about end-of-life, hospice, and palliative care. They know that patients have the right to make their wishes known, often via advance directives and related measures.

Physicians and other health care practitioners have always played a major role in health care decision making. However, for various reasons such as misunderstanding, unfamiliarity with related processes, and disinterest, this participation has been inconsistent and sometimes obstructive. The purpose of this article is to clarify those processes, including the physician's role in relation to them.

Underlying Principles

Health care decision making, including that associated with end-of-life care, involves medical, philosophical, and legal precedents. The Patient Self-Determination Act of 1991 reinforced patients' rights to accept or refuse specific medical care and to identify a legal representative to make health care decisions for them if they lack capacity. In 1993, Maryland passed the Health Care Decisions Act (HCDA), a comprehensive law regarding individual rights to make health care decisions. The HCDA also details the procedures to follow when patients are incapable of making health care decisions.

Consistent, systematic processes are essential in order to address relevant issues and accommodate diverse values and desires effectively.¹ In the health care community, there are varying degrees of understanding of the issues, including the meaning and implications of the right to decline life-sustaining treatments.

Problems and disputes about ethical decisions often result from disagreements about conclusions that arise from different understanding of facts, diverse underlying assumptions, or dif-

ferent criteria for drawing those conclusions. Even when participants concede their differences, the sources of disagreement may not be adequately understood and reconciled.

Health Care Decision-Making Processes

Health care decision making (including that related to palliative, hospice, and end-of-life care) involves the convergence of issues from two major directions: 1) the "patient-centered" direction that considers a person's wishes, goals, and current capacity for reviewing information; and 2) the "provider-centered" direction that considers a patient's condition and prognosis and the relevance of potential treatment options.

Table 1 identifies the key steps in the health care decision-making process and key physician roles at those steps. Each step (e.g., clarifying medical issues and identifying a primary decision maker) is important to the overall result. It is best to follow the steps sequentially, to the extent possible, even under challenging circumstances such as emergencies and acute condition changes.

Identify Situations Where Health care Decision Making Is Needed

An early step in the health care decision-making process is to recognize situations (e.g., terminal condition, progressive irreversible decline in function) that warrant discussion of treatment options and documentation of specific choices. It is important to identify individuals who have done, or who wish to do, advance care planning and situations where advance care planning is more urgently indicated.

Some individuals have already participated in advance care planning and have made decisions and/or documented their wishes (for example, a "No CPR" decision in the hospital prior to transfer to a post-acute care facility). Even in settings where oth-

ers are involved in promoting discussions about health care decision making (e.g., hospitals and nursing homes), physicians should at least raise the subject when a patient situation warrants it.

Identify and Clarify Existing Care Instructions

Federal and state laws require health care providers to inform individuals of their right to make health care decisions and document advance directives. The goal of this step is to identify individuals who have existing written care instructions or have otherwise previously made decisions related to life-sustaining treatments and end-of-life care.

It is important to clarify the content and implications of existing advance directives and other care decisions. Patients and their families may not be fully aware of the content, or

clear about the implications, of their own advance care planning documents or those of the person for whom they are acting.

Health care choices are generally either treatment-specific or situation-specific. For example, a treatment-specific directive might say, "I do not want to be placed on a ventilator under any circumstances." A situation-specific directive might specify not to use aggressive medical interventions if they are deemed to no longer be likely to make a difference in the outcome or improve quality of life.

Sometimes, advance directives are too general, too specific, or self-contradictory. Or, they may place conditions (e.g., confirmation of a terminal or end-stage condition) on the implementation or withholding of specific treatments. Care instructions limiting specific treatment options (e.g., CPR) may or may not limit the evaluation and treatment of other medical conditions.

Clarify Medical Issues

"Quality of life" and "quality of care" are inseparable in all settings. Medical condi-

tions affect function and quality of life and impact the potential for improving someone's overall status and prognosis.

Clarifying underlying causes of impaired function and quality of life is essential to identifying the relevance and risks of treatment options, recognizing situations where advance care planning is urgent, and recognizing factors affecting decision-making capacity. The physician helps clarify prognosis (e.g., how likely is someone to stabilize, improve, decline, or die). For example, is the patient at risk for recurrent episodes of acute respiratory failure after having been treated for it during a recent hospitalization?

Health care practitioners commonly

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face situations that are not discussed explicitly in advance directives or where it is unclear whether and how a directive applies. It is often necessary to consider whether and how such instructions apply and to try to extrapolate the general tone or direction of a patient's wishes or instructions. Thus, physicians should not only ask about advance directives but should review them, and not just rely on someone else to interpret them.

For example, a patient may document the general wish to decline life-sustaining treatments if a doctor determines that it is unlikely that the tests and treatments would improve or restore a desirable quality of life. Several years later, that person may suffer a head injury, stroke, or pneumonia. Then or at any subsequent time of illness, several vital questions must be answered: What is the prognosis? Is the situation hopeless? Are life-sustaining procedures indicated? To what extent could treatment be successful? If treatment could potentially reverse the acute condition, would it have a significant impact on the overall prognosis and quality of life?

It is important for physicians to distinguish potentially treatable acute situations (e.g., delirium or medication side effects) from exacerbations of irreversible chronic problems or a terminal condition. An acute change in cognition and function, though often correctable, may temporarily affect decision-making capacity and may erroneously appear to portend an end-of-life situation (e.g., in a patient with pre-existing dementia).

Define Decision-Making Capacity (DMC)

Clarifying DMC is essential to optimizing individual participation in personal and health care decisions. Certifications related to DMC can have major implications for a patient's subsequent opportunities to influence his or her care. Thus, physicians should

take their role in DMC determination seriously.

The HCDA requires that a practitioner confirm DMC. However, decision-making capacity is a functional capability that is influenced by medical conditions, functional impairments, and psychosocial factors (e.g., education). A single test or assessment result is generally not definitive. DMC is often not "all-or-none," but can be partial, at several levels.

It is often useful to try to get input about care decisions even from patients with medical conditions affecting DMC. For example, a patient who cannot readily discuss the rationale for whether he or she wants a feeding tube may still try to pull out an indwelling tube or repeatedly state "I don't want it."

DMC determinations should be based on performance over time, not just on one occasion. However, physicians vary in understanding the concept of DMC and the extent of their involvement in determining DMC in individual patients. Also, it may be harder to get details about a patient's function and cognition in the community than in an inpatient setting.

There is published guidance about determining DMC. For example, Applebaum and Roth have suggested four performance levels relevant to determinations of DMC²: 1) Evidencing a choice, 2) Factual awareness of issues, 3) Rational manipulation of information, and 4) Appreciation of the nature of the situation. Physicians who are involved in these capacity determinations should familiarize themselves with related criteria and processes.

Although DMC determinations are often straightforward, opinions about a given patient may be contrasting and equivocal. Various assessors may use different criteria. Thus, it is essential to indicate the basis for such conclusions and to reconcile different opinions about a patient's DMC.

Identify the Primary Decision Maker

The HCDA protects the rights of competent individuals to make their own health care decisions. However, many patients have partially or totally impaired DMC. If it is determined that a patient lacks sufficient DMC for the decision-making situation, the HCDA specifies a sequence of involvement, restrictions, and process requirements for substitute decision makers.

Physicians should be aware of the law's requirements related to substitute decision making. Such awareness should include the law's stipulation that substitute decision makers cannot simply override someone's expressed wishes and substitute their own.

Some substitute decision makers try to go against the previously documented wishes of a patient who no longer has sufficient DMC. They may badger or threaten physicians and other providers relentlessly to yield to their wishes. Ultimately, it is a physician's ethical and legal responsibility to try to protect and enhance a patient's rights to direct his or her own care, to the extent possible. The HCDA confers legal immunity for decisions made in good faith and by following the law's prescribed processes.

Certify the Existence of Any Qualifying Conditions

Situations often arise where physicians must certify the existence of a qualifying condition in order to permit substitute

decision makers to act on behalf of a patient to withhold or withdraw potential life-sustaining treatments. The HCDA identifies three such situations: 1) end-stage condition, 2) terminal condition, and 3) persistent vegetative state.

Physician involvement in these determinations is common and often crucial. Although the HCDA defines these situations, it does not provide detailed criteria for identifying their existence. It is important for physicians to be familiar with the definitions and to understand their role in determining that a qualifying condition is present.

The medical literature provides some guidelines for considering the permanence of a vegetative state.³ The HCDA's definition of persistent vegetative state focuses on the awareness of self and surroundings and does not attempt to specify any duration of unconsciousness as a marker of persistence.

As with DMC determinations, it helps to look at medical issues in the context of the patient's overall condition and prognosis. For example, patients with end-stage kidney disease or chronic obstructive pulmonary disease may or may not be end-stage functionally. Conversely, a patient may be terminal or end-stage despite not having a specific identifiable end-stage or terminal illness. Instead — especially in the frail elderly — an aggregate of conditions may cause overall physical and functional decline. Such distinctions are sensible and physiologically valid.

Define and Present Relevant Issues and Options

Patients often need help to understand how specific treatment options might relate to their general goals and wishes. The practitioner is in a unique position to explain this, by linking treatment options to goals.

Most patients and family members need additional information and assistance to make or update treatment choices. When done properly, the preceding steps facilitate presenting the issues and options (e.g., whether to resuscitate, hospitalize, or provide artificial nutrition and hydration) to a patient or substitute decision maker. The manner and methods used to present information can influence patient and

substitute decision maker understanding of issues and their potential for making appropriate decisions.

Despite time constraints and the pressures of emergency situations, it is crucial to define the issues as clearly as possible before trying to address them. Although knowledgeable social workers and nurses can give general guidance on procedural issues (such as how to complete advance directives), practitioners need to discuss the pertinence, benefits, risks, and advisability of specific treatment options.

Interventions (e.g., hospitalization, medical testing, resuscitation, and artificial nutrition and hydration) should be relevant to a person's values, goals, wishes, and overall condition and prognosis. Thus, for instance, surgery may correct acute abdominal distension with fever by removing a section of infarcted small intestine in someone with mesenteric artery occlusion. But the broader consequences of the procedure for further improvement, or for sustaining a desirable quality of life, may be marginal.

It is important for physicians to recognize that effectiveness should relate to the overall objective of treatment in general, not just to managing a specific disease or condition. The HCDA does not require or suggest that the physician must offer all treatment options, regardless of their pertinence. It gives physicians the option to decline to offer treatments that are deemed to be medically ineffective (which is not the same as "ethically inadvisable").⁴

It is important to help patients keep the issues straight. Resuscitation (CPR) status should be distinguished from wishes about treatment prior to cardiopulmonary arrest. Patients who decline CPR may still want — and be able to benefit from — other medical treatments. Or, they may only desire select interventions (e.g., dialysis or artificial ventilation), but not others (e.g., artificial nutrition or hydration).

Implement Choices Related to Health care Decisions

Orders are needed to implement specific choices to withhold or withdraw treatments. They should be consistent with a patient's valid choices as well as with applicable laws and regulations.

The components of palliative care can vary considerably among patients, depending on factors such as their condition and choices. Orders should specify relevant aspects of any limited interventions or palliative care plan — that is, what exactly will not be provided. Orders written as “comfort care” or “palliative care” are too vague to guide precise and consistent interpretation.

Review the Situation and Continue or Modify Approaches, as Appropriate

This step involves revisiting the previous steps, based on periodic re-evaluation of a patient’s condition, prognosis, and wishes. Interventions may be continued, discontinued, or adjusted, as appropriate.

A patient’s situation may change with time or additional decisions may be needed as new issues arise. Capable patients have the right to change or revoke their advance directives, and substitute decision makers can change their instructions within limits (e.g., they must remain consistent with a person’s documented wishes). The HCDA has specific procedural requirements for making changes.

Updating of related medical orders should be done within a time frame that is relevant to changes in a patient’s prognosis, condition, and wishes. Sometimes, new or revised documents and orders are needed to implement revised or new treatment choices.

Decision-making capacity may change with time as existing conditions resolve or new illnesses and condition changes occur. The physician may need to re-evaluate a person’s DMC or verify that it is irreversible.

Summary

Health care decision making is a process that includes definable steps in a desirable sequence. The process is universally relevant (i.e., it applies in all settings) and enduring (i.e., it has remained applicable over time and will continue to apply in the future).

Physicians play an essential role in the health care decision-making process. Learning to follow desired approaches at each step (e.g., optimal approaches to defining DMC) facilitates and improves the quality and pertinence of physician participation.

Generally, diligent adherence to the steps in this process is likely to yield the best possible results — they are consistent with patient needs and values while facilitating pertinent utilization of health care resources — under often challenging and imperfect

circumstances. Thus, the health care decision-making process constitutes a key component of the improvement and reform of health care, which is currently under much critical scrutiny.

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**TABLE I
THE HEALTH CARE DECISION-MAKING PROCESS FRAMEWORK**

PROCESS STEP	PHYSICIAN ROLES	SOME KEY ISSUES
Identify situations where health care decision making is needed	Help identify situations that warrant discussion of treatment options and documentation of specific choices	Decision making may be routine or may be needed because of acute medical illness or significant risk of complications
Identify and clarify existing care instructions	<ul style="list-style-type: none"> - Inquire about existing documents related to wishes regarding life-sustaining treatment and end-of-life care - Help identify individuals who wish to initiate or update advance care planning 	<ul style="list-style-type: none"> - For facility-based (e.g., nursing home) patients, staff can assist - Existing documents are often somewhat ambiguous or incomplete - Patients and families may be unfamiliar with the content, or unclear about the implications of, advance care planning documents
Clarify medical issues	Help clarify factors affecting a person's physical condition, function, quality of life, prognosis, and decision-making capacity (DMC) <ul style="list-style-type: none"> - Help define prognosis 	<ul style="list-style-type: none"> - Defining problems, impairments, and risks, and their underlying causes, is key to identifying situations where advance care planning is urgent, understanding relevance and risks of treatment options, and recognizing factors affecting DMC
Define decision-making capacity	<ul style="list-style-type: none"> - Help assess and define DMC - Document the rationale for conclusions about decision-making capacity - Address, as indicated, treatable underlying causes of impaired mental and physical function that affect decision-making capacity 	<ul style="list-style-type: none"> - This step is essential to optimizing individual participation in personal and health care decisions - Decision-making capacity may change with time as existing conditions resolve or new illnesses and condition changes arise
Identify the primary decision maker	<ul style="list-style-type: none"> - Help define a patient's role in making health care decisions, based on decision-making capacity and on other pertinent factors 	<ul style="list-style-type: none"> - An impaired patient may still be able to participate to some extent in advance care planning or treatment selection
Certify the existence of any qualifying conditions	<ul style="list-style-type: none"> - Help identify whether the patient meets criteria for end-stage condition, terminal condition, or persistent vegetative state 	<ul style="list-style-type: none"> - Certification of these conditions must be compatible with definitions in the HCDA
Define and present relevant health care issues	<ul style="list-style-type: none"> - Help define specific issues that need discussion or decisions - Present and discuss the pertinence, benefits, and risks of various treatment options 	<ul style="list-style-type: none"> - It is important to clearly and correctly identify the issues before trying to address them -Cardiopulmonary resuscitation (CPR) status should be distinguished from wishes about treatment prior to any cardiopulmonary arrest
Implement choices related to health care decisions	<ul style="list-style-type: none"> - Give medical orders to implement treatment and care choices 	<ul style="list-style-type: none"> - Orders should be consistent with applicable laws and regulations and with valid choices made by a patient or a substitute decision maker - Orders should specify relevant aspects of any limited care plan; i.e., what exactly will not be provided
Review the situation and continue or modify approaches, as appropriate	<ul style="list-style-type: none"> - Periodically re-evaluate a patient's condition, prognosis, and wishes - Continue to adjust approaches as needed 	<ul style="list-style-type: none"> - An individual's situation may change with time, or the individual or substitute decision maker may change his or her wishes about treatment choices

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