Health Care Decision-Making Capacity: A Legal Perspective for Long-Term Care Providers

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While federal law establishes guidelines that designated facilities must follow in providing information about a patient’s rights regarding self-determination in the health care decision-making process, state law determines the decision-making process and the legal requirements pertaining thereto. A person’s capacity to make health care decisions or to have the authority and capacity to delegate the right to make such decisions is a legal conclusion based on statutory and common law principles. This article discusses the legal perspective of capacity in health care decision making and the legal framework of the question of whether or not a person has the capacity to make health care decisions. Western civilization’s concepts of personal autonomy and self-determination are at the core of health care decision making, but health care providers must be aware that other cultures do not always share that value system. Sensitivity to multicultural diversity in this context is imperative to maintain individual self-esteem and respect, both for the patient and the patient’s family. (J Am Med Dir Assoc 2006; 7: 322–326)

INTRODUCTION

The inherent right of an individual to make his or her own decisions regarding health care is so deeply ingrained in our society that for most health care professionals and their patients it is a “given.” The health care professional will diagnose a condition, describe the suggested course of treatment to the patient and the patient will agree or not agree to the recommended action. Rarely is any thought given to underlying concepts upon which this dialogue is based or the assumptions inherent in the dialogue.

However, upon closer examination, it becomes clear that a number of legal/medical/cultural concepts and assumptions are at work here. When one or more of those concepts or assumptions are removed or challenged, problems can arise. Four of the most common of these underlying assumptions are the following:

1. that the patient understands the health care professional’s diagnosis and recommendation;
2. that the patient possesses the capacity to make an informed decision regarding the recommended course of treatment;
3. that the patient is able to communicate the decision; and
4. that the patient wishes to participate in the decision-making process in the first place.

In dealing with residents of skilled nursing facilities and other long-term care facilities, it has been the author’s experience that health care professionals and their legal advisors frequently find that one or more of these underlying concepts or assumptions are lacking (or are perceived to be lacking). This article explores the current legal framework for health care decision making in the United States and the impact of federal and state law (both statutory and judicial) on the relationship between the health care professional and the patient in a long-term care environment.

DISCUSSION

To properly analyze whether or not a patient has the capacity to make a health care decision, it is necessary, from a legal standpoint, to understand the following:

1. What is “health care”; and
2. What is a “health care decision”; and

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The definitions of these 3 terms, "health care," "health care decision," and "capacity" are governed by state, not federal, law. As will be discussed, federal law impacts the discussion in the context of (1) a health care provider's duty to inform the patient of his or her rights regarding his or her ability to execute an Advance Health Care Directive under the Federal Patient Self-Determination Act, and (2) that the right of the individual and the individual's surrogates to make health care decisions is constitutionally protected under the US Constitution. Otherwise, the "details" of what constitutes "health care," "health care decision," and "capacity" is determined on a state-by-state basis.

Because these definitions vary state by state, for purposes of this discussion, reference will be made to the Uniform Health Care Decisions Act adopted by the National Conference of Commissioners on Uniform State Laws and recommended to the states for adoption in 1993 (hereafter referred to as "the Act"). As of May 2005, 8 states have adopted the Act as proposed (Alabama, Alaska, Delaware, Hawaii, Maine, Mississippi, New Mexico, and Wyoming), while other states have modeled their own versions on the Act. (See, for example, California's Health Care Decisions Law, Probate Code §§4600–4805, based in part on the Uniform Act.) The Act, by its terms, supersedes 3 previous Uniform Acts, namely, the Model Health Care Consent Act (1982), the Uniform Rights of the Terminally Ill Act (1985), and the Uniform Rights of the Terminally Ill Act (1989). States that have adopted these acts or versions of them and then adopt the Act, are advised to repeal the prior statutes.

Under the Act, "health care" means "... any care, treatment, service, or procedure to maintain, diagnose, or otherwise affect an individual's physical or mental condition." A "health care decision" under the Act is defined as "a decision made by an individual or the individual's agent, guardian, or surrogate, regarding the individual's health care, including:

(a) selection and discharge of health care providers and institutions;
(b) approval or disapproval of diagnostic tests, surgical procedures, programs of medication, and orders not to resuscitate; and
(c) directions to provide, withhold, or withdraw artificial nutrition and hydration and all other forms of health care."

In light of the recent controversy revolving around the late Terry Schiavo, it is important to note that nutrition and hydration are specifically considered to be elements of "health care" under the Act, and decisions regarding nutrition and hydration are specifically considered to be "health care decisions."

The applicability of the Act in the long-term care setting is again made definitively. A "health care institution" is defined as "... an institution, facility, or agency licensed, certified, or otherwise authorized or permitted by law to provide health care in the ordinary course of business." Similarly, "health care provider" is defined as "... an individual licensed, certified, or otherwise authorized or permitted by law to provide health care in the ordinary course of business or practice of a profession.

"Capacity" in the legal lexicon and therefore, as a result, in the health care lexicon as well, has replaced the term "competent" in this context (see, for example, Ganzinzi et al). "Capacity" is defined as "... an individual's ability to understand the significant benefits, risks, and alternatives to proposed health care and to make and communicate a health care decision." It is critical to this discussion to understand there are at least 3 components to the definition of "capacity" in the context of health care decision making:

(1) the ability to "understand";
(2) the ability to make a health care decision; and
(3) the ability to communicate that decision.

As noted above, the Act has been adopted in only 8 states to date, but is a reference point for states that have adopted their own statutes. For example, the California definition of "capacity" to make a health care decision varies slightly (but significantly) from that of the Act. California's statute under its Health Care Decisions Act provides: "Capacity' means a person's ability to understand the nature and consequences of a decision and to make and communicate a decision, and includes, in the case of proposed health care, the ability to understand its significant benefits, risks and alternatives."

However, California has a different definition of capacity to give informed consent in its sections dealing with legal mental capacity (known as the Due Process in Competence Determination Act or DPCDA). Under DPCDA, for purposes of judicial determination of capacity (ie, a judicial proceeding such as a guardianship or conservatorship), a person "... has the capacity to give informed consent to a proposed medical treatment if the person is able to do all of the following:

(1) Respond knowingly and intelligently to queries about that medical treatment.
(2) Participate in that treatment decision by means of a rational thought process.
(3) Understand all of the following items of minimum basic medical treatment information with respect to that treatment:
(A) The nature and seriousness of the illness, disorder, or defect that the person has.
(B) The nature of the medical treatment that is being recommended by the person's health care providers.
(C) The probable degree and duration of any benefits and risks of any medical intervention that is being recommended by the person's health care providers, and the consequences of lack of treatment.
(D) The nature, risks and benefits of any reasonable alternatives.

(b) A person who has the capacity to give informed consent to a proposed medical treatment also has the capacity to refuse consent to that treatment."
It should be obvious to even the most casual reader that the test used by a court in determining capacity to give informed consent in a judicial proceeding governed by a statute such as this is much more stringent than the test imposed by the Act, ie, "... an individual's ability to understand the significant benefits, risks, and alternatives to proposed health care and to make and communicate a health care decision."14

So how does a health care professional determine medical decision-making capacity under either of these types of tests? The short answer is, "he or she does not," "Capacity" in this context, however defined, is a legal conclusion based on empirical evidence. The health care professional's conclusion of whether or not the patient has medical decision-making capacity is not determinative; it is one piece of evidence or opinion that the attorney or judge uses in determining from a legal standpoint whether or not the patient has health care decision-making capacity.

If that distinction does not complicate the picture enough for the health care professional, then the fact that, under many states' laws one can have capacity to do one thing and lack capacity to do another, complicates the picture even more. The tests for capacity that are being discussed in this article cover health care decision making only; they do not cover capacity to enter contracts, make estate plans, or marry. Each of those activities carries its own test in many jurisdictions.

Consider the following hypothesis:

Jacob is an 84-year-old widower with 3 children and 6 grandchildren. Two years ago he suffered a stroke that left him unable to walk or speak. He has short-term memory loss but is able to recognize his children and grandchildren. With assistance, he can write his names on a magnetic board using magnetized letters. He enjoys watching baseball games on television and appears able to follow the game. He appears to hear and understand what is said to him and sometimes appears to be trying to comply with oral requests for specific actions such as "raise your left hand." He lives in a skilled nursing facility.

Does Jacob have capacity? To contract? To marry? To make a will? To make health care decisions? The answer is "we don't know." On the one hand, under most state laws, if Jacob knows who his family is and the general nature of his assets (a fact we don't know) and to whom he wants to leave his estate, he may well have testamentary capacity and be able to execute a will. On the other hand, if the medical and legal professionals cannot ascertain that information because of Jacob's inability to communicate, the answer may be "no."

Examining the situation further, Jacob probably does not have the capacity to contract, given his memory and physical problems. However, let us assume that Jacob is informed that a tumor has been discovered, that it is operable and he is told that his chances of recovery from the surgery are good. Jacob responds by spelling out on his magnetic board "no surgery." Is this a "rational" decision by Jacob? Does Jacob have the legal capacity to make this decision? Based on the facts given, we do not know. But the mere fact of his current physical condition and limitations is not, in and of itself, evidence of a lack of capacity to make health care decisions. That is frequently a difficult concept for health care providers to understand. In order to properly evaluate Jacob's decision-making capacity, the health care provider and the legal professional must look beyond Jacob's physical situation and examine his mental state in depth and, specifically, to determine the answer to the question. Most important, all parties must understand that they cannot imbue the situation with their own perspectives, biases, or belief systems. What any of them would do in this situation is not necessarily what Jacob would do.

If the subject of health care decision-making capacity were not complicated enough, there are 2 related issues that must be kept in mind:

1. Our societal focus on autonomy in health care decision making is just that: our societal focus, ie, a Western European/Judeo-Christian socio-political construct. Not all cultures have such a strong emphasis on autonomous health care decision making; and
2. Federal statutory mandates compel health care providers to counsel patients and their families regarding autonomous health care decision making in ways that may not be welcomed by the patient or the family and may prove to be counterproductive from a healing standpoint.

CULTURAL DIVERSITY ISSUES

A discussion regarding cultural diversity in the context of health care decision making is far beyond the scope of this article. However, it must be noted that many cultures not only do not put as high a value on self-determination and informed consent as our dominant, European-focused culture does, they do not consider it a value at all (for a general introduction to this subject see Zimring15). Other cultures and religions reject the concept because their views of medical practice, healing, the afterlife, or intergenerational communication conflict with one or more of the principles and concepts involved in patient self-determination, informed consent, and the use of advance directives.

A few examples will illustrate the issue:

Seniors of Asian or Pacific Island backgrounds, as well as Mexican Americans, come from cultures that have strong traditions that focus on the family as the predominant unit rather than the individual.16 Family involvement in health care decision making and filial piety mandates that children care for and respect their parents. As a result, studies have shown that Mexican Americans are less likely to believe that the patient should be told the diagnosis and that medical decision making should be made by the family.17 In this context, autonomy is not viewed as empowering, but rather is perceived as isolating and burdensome.16

Another example occurs among Navajo Native Americans. They believe that thought and language have the power to shape reality and to control events. Traditional beliefs regarding healing require people to "think and speak in a positive way."19 In addition, the traditional Navajo belief is that health is maintained and restored through positive ritual language. Thus, when health care providers engage a Navajo
Native American in an informed consent discussion and disclose the possible risks of a proposed course of treatment, they are speaking in a “negative way,” violating the Navajo prohibition.

Thus, health care providers, especially in a long-term care setting where the patient oftentimes is unable to inform the providers regarding issues of culture and religion, need to be mindful and circumspect in dealing not only with the patient, but with the patient’s family. There should be an exploration of any cultural issues that may be present before a discussion of health care decision making takes place, regardless of whether or not the patient has capacity.

**FEDERAL PATIENT SELF-DETERMINATION ACT ISSUES**

Finally, there is the issue of the information health care providers are required to provide under the Federal Patient Self-Determination Act (PSDA).20

As a condition to participation in the Medicare and Medicaid programs, certain institutional health care providers, including skilled nursing facilities, home health care agencies, hospice programs, hospitals, and prepaid health care organizations are required to furnish their patients with information about advance directives. It is important to note that the statute does not require that patients have advance directives, only that they be provided information regarding them.21 The content of information to be provided is governed by state law and by each institution’s policies.

Covered health care providers are required to maintain written policies and procedures applicable to all adults receiving medical care. The policies and procedures must describe the patient’s rights under state law to make decisions regarding the patient’s medical care, including the right to accept or refuse treatment and the right to make an advance directive. It should be noted that the PSDA applies to a patient’s medical decision-making rights in general, not just the right to execute an advance directive.

To implement this, the law requires that a patient (or a family member or surrogate, if the patient is incapable of receiving the information) be given written information regarding the patient’s rights under applicable state law. The health care provider’s written policies regarding the implementation of the patient’s rights must also be provided.22 Since the information is to be given to the patient if the patient is capable of receiving the information, and to a family member or surrogate only if the patient is incapable of receiving the information, the issue of capacity once again is presented as a threshold issue in determining who is to receive the information.

The information is to be provided to the patient at the time of admission as a resident to a skilled nursing facility, as an inpatient in an acute care facility, in advance of the patient coming under the care of a home health agency, or at the time of initial receipt of hospice care by a hospice agency.23 Since physicians are rarely present at these points in time, it is critical that health care providers properly educate their admissions personnel and other “front-line” staff in appropriate, basic protocols specifically designed to determine what constitutes a “questionable case” so that appropriately trained staff (whether medical or legal), can be consulted on the issue of health care decision-making capacity.

Thus, while the PSDA mandates that covered health care organizations provide patients or their family or surrogates with information regarding their health care decision-making rights, including the right to have an advance directive, there is no requirement under either federal or state law that patients have such documents.

**QUESTIONS**

1. A person’s capacity to make health care decisions for him or herself is determined by:
   (a) The patient’s attending physician
   (b) The administration of a Mini-Mental Status Examination
   (c) The patient’s psychiatrist
   (d) Applying legal standards defining capacity under state law
   (e) None of the above

2. Under the Uniform Health Care Decision-Making Act a “health care decision” includes:
   (a) Selecting and discharging health care providers and institutions
   (b) Approving and disapproving surgical procedures
   (c) Approving and disapproving Order Not to Resuscitate
   (d) Providing or withholding artificial nutrition and hydration
   (e) All of the above

3. Patient self-autonomy is:
   (a) Valued by all cultures and religions
   (b) A right guaranteed by the US Constitution
   (c) Within the discretion of the health care provider
   (d) Recognized by only a few states
   (e) None of the above

4. The Federal Patient Self-Determination Act:
   (a) Applies to all health care providers regardless of the sources of their funding
   (b) Requires every patient to have an advance directive or health care proxy
   (c) Only applies to acute care facilities
   (d) Requires that patients be provided with certain information about their health care decision-making rights under state law

5. A patient who has health care decision-making capacity:
   (a) Must sign an advance directive when entering a health care facility
   (b) Can choose to delegate his or her health care decision-making authority to another person called a surrogate
   (c) Must communicate health care decisions verbally and in English
   (d) Must communicate health care decisions in writing and in English
   (e) None of the above
REFERENCES

1. Federal Patient Self-Determination Act, 42 USCA §1395cc(f)(1) and 42 USCA §1396a(a) (2004).
20. 42 USCA §1395cc(f)(1).
21. 42 USCA §§1395cc(f)(1), 1396(a)(1), 1396a(w)(2).