

Scripps Gerontology Center

Scripps Gerontology Center Publications

Miami University

Year 1996

The patient-doctor relationship and
advance directives : implications for
long-term care in Ohio

Terry Perlin
Miami University, commons@lib.muohio.edu

Ohio Long-Term Care Research Project

**THE PATIENT-DOCTOR
RELATIONSHIP AND
ADVANCE DIRECTIVES:
IMPLICATIONS FOR
LONG-TERM CARE
IN OHIO**

Terry M. Perlin

January 1996



Terry M. Perlin is a Professor in the School of Interdisciplinary Studies and a Fellow with the Scripps Gerontology Center at Miami University, Oxford, Ohio. He received his Ph.D. from Brandeis University in 1970 concentrating in social and political philosophy. He is the author of *Clinical Medical Ethics: Cases in Practice* (Boston: Little, Brown and Co., 1992). Dr. Perlin serves as consultant in medical ethics at The Jewish Hospitals, Cincinnati, Ohio and San Francisco General Hospital. He is a member of the Board of Trustees of the Bioethics Network of Ohio.

Acknowledgement:

Consultant for this project was Barbara Morris, M.D., Department of Family Medicine, University of Cincinnati College of Medicine.

This research was funded by a grant from the State of Ohio, Board of Regents, Ohio Long-Term Care Research Project. Reprints available from the Scripps Gerontology Center, Miami University, Oxford, OH 45056; (513) 529-2914; FAX (513) 529-1476.

**The Patient-Doctor Relationship and Advance Directives:
Implications for Long-Term Care in Ohio**

Terry M. Perlin

**Scripps Gerontology Center
Miami University
Oxford, OH 45056**

January 1996

Table of Contents

INTRODUCTION	1
METHODS	1
BACKGROUND	2
The Patient Self-Determination Act and the Principle of Autonomy	2
Living Wills	3
Durable Power of Attorney for Health Care	4
Patient Expectations	4
Advance Directives in Ohio	5
FINDINGS	6
The Patient-Doctor Connection	6
Re-forming the System	8
RECOMMENDATIONS	12
PATIENT/CLIENT GUIDE	15
REFERENCES	17

Introduction

Who will speak for you when you can no longer decide what sorts of medical treatment you want to accept or decline? How will such persons know your views and values? Is there any way that you can provide, in advance and with a reasonable degree of certainty, that the kinds of treatments you may receive will serve previously declared interests? And, if you are unconscious or without cognitive capacity, can there be assurance that you will not be kept alive indefinitely by sophisticated machines or medications? These questions are at once clinical and ethical. Even if they can be answered satisfactorily, it still remains a challenge to find practical and concrete ways of stating one's views and trying to guarantee that advance planning will be carried out. There is perhaps only one certainty when health care determinations must be reached: *a physician of record will be at or near the center of decision-making.*

The focus of advance directives legislation has been on end-of-life decision making.

This project investigates the role of advance directives in the patient-physician relationship. On December 1, 1991, the federal *Patient Self-Determination Act* went into effect. (OBRA, 1990) This law requires hospitals, nursing homes, and other health care providers to inform patients (and clients)

about both state law and institutional policy regarding formal means of controlling decisions about their health care if the patient becomes incapable of making a health care decision due to mental incapacity. The PSDA has encouraged states to pass or refine laws which allow patients to formulate advance directives such as living wills and durable powers of attorney for health care. The focus of advance directives legislation has been on end-of-life decision making.

Putting such legislation into practice has, however, proven more difficult than drafting or passing laws. Individual adults -- most of them situated in families -- must complete advance directives. Lengthy and detailed conversations are necessary in order to clarify values and achieve informed decision-making about, for example, views on withholding or withdrawing life-sustaining treatments. This project examines the role of physicians, working with patients prior to "crisis moments" in health care, in the advance directives process.

Methods

A comprehensive search of the relevant medical, nursing, public health, public policy, and medical ethics literature, aided by such research tools as MEDLINE, AGELINE, and BIOETHICSLINE, yielded important recent data, at the national level, on advance directives. In addition, research in law reviews and court cases produced several analyses of advance directives in the state of Ohio. The results of a state-wide survey of ethics committees in long-term care facilities in Ohio were analyzed and discussed with the author of the study.

Theoretical and empirical studies revealed that few investigators have directly asked physicians about their views on ADs.

The project entailed three related field-observational and interview processes: (1) on-site observations at long-term care facilities, medical centers and physicians' offices; (2) discussions with nursing home personnel and leaders of state-wide organizations; (3) focus group discussions with doctors in private (individual and group) practice as well as medical school faculty. The latter process involved arranging and holding in-depth question and answer sessions -- co-facilitated by the project consultant, a family physician and medical school professor -- on three separate occasions. Collation and analysis of focus group commentary followed; an executive summary of the commentaries by the author and consultant resulted in a statement of research results and policy recommendations.

Background

Health care professionals have expressed support for patient or client autonomy.

The Patient Self-Determination Act and the Principle of Autonomy

The adult patient's right to self-determination has its roots firmly grounded in the concept of individual autonomy. *Autonomy* refers to self-rule or self-governance. In health care, this concept is

applied to competent patients in their consent to or refusal of medical treatment and intervention. As long as patients have the capacity to engage in health care decision making, their right to self-determination is valued and respected. Health care professionals have expressed support for patient or client autonomy. For example, social workers' commitment to respecting patients' self-determination is expressed in the *NASW Code of Ethics* (National Association of Social Workers, 1994).

The Patient Self-Determination Act addresses the extension of adult, competent individuals' rights to incompetent individuals through the formulation of advance directives. The act requires that health care providers that accept Medicare and Medicaid funding, including hospitals, skilled nursing facilities, home health agencies, hospice programs, and health maintenance organizations, meet the following requirements:

- maintain written policies and procedures respecting advance directives and provide their patients with copies of such policies and procedures;
- provide each patient with written information concerning patients' rights to make decisions concerning medical care, including the right to accept or refuse medical or surgical treatment;
- document in the patient's medical record whether an advance directive has been executed; and
- provide education for staff and the community on issues concerning advance directives.

Health care providers are prohibited under the law from discriminating against individuals on the basis of the existence of an advance directive. Providers are also obligated to inform patients of their policies and procedures to respect patients' advance directives. If the health care provider objects to the implementation of the advance directives on the basis of conscience, most states have laws that allow for such objections.

The Patient Self-Determination Act defines *advance directive* (AD) as a "written instruction, such as a living will or durable power of attorney for health care, recognized under State law and relating to the provision of such care when the individual is incapacitated." (OBRA, 1990)

Living Wills:

Living wills are instructional documents that detail patients' preferences regarding future treatment decisions. In contrast, durable powers of attorney for health care "vest patients' future decision-making rights in specific persons" (Pellegrino, 1992, p. 354) when patients become incapacitated. Most authorities state that patients who have preferences would profit from having both a living will and a durable power of attorney for health care. Physicians, nurses, social workers, and personal attorneys typically encourage patients to enact a durable power of attorney for health care when ever a surrogate decision maker is available, because living wills are by definition inflexible, in that they spell out in advance what the patient wishes to occur in certain circumstances. In Ohio, however, if a living will and a DPOA are in conflict, the living will takes precedence.

The inflexibility of a living will may be useful when, for example, it encourages the family and treatment team to withhold or withdraw treatments as the patient wishes. However, because the patient is not able to foresee all circumstances at the time the living will is written, that same inflexibility may prevent decisions the patient may have wished. If the wording of the living will is followed strictly, the patient may not receive the beneficial treatment that could restore her health.

Living wills become effective only when a patient is in a terminal condition, when death is imminent, or when the patient is in a persistent state of unconsciousness. By contrast, use of a surrogate decision-maker may carry out the patient's wishes even in non-terminal cases. Whenever one loses the ability to make health care decisions, the Durable Power of Attorney for Health Care goes into effect.

Even when a patient does have a surrogate decision maker, living wills are useful because they provide clear and convincing evidence of the patient's wishes.

Even when a patient does have a surrogate decision maker, living wills are useful because they provide clear and convincing evidence of the patient's wishes. In some states, such as Ohio, some life-sustaining procedures such as artificial nutrition and hydration cannot be forgone without such evidence.

Durable Power of Attorney for Health Care:

The Durable Power of Attorney for Health Care (DPOAHC) designates a surrogate who can make decisions pertaining to medical treatment when the patient lacks decision-making capacity. Surrogate decision making can be based either on the substituted judgment standard or on the best interest standard. The *substituted judgement standard* requires the surrogate decision maker to make the same decision that the patient would have made. This standard permits the patient to exercise the right to self-determination after incompetence. Written documents specifying the patient's wishes and communication about the patient's values and religious beliefs make the substituted judgment possible. The cases of Karen Ann Quinlan (*In re Quinlan*, 1976) and Nancy Beth Cruzan (*Cruzan by Cruzan v. Director*, 1990) are examples of families exercising substituted judgment.

In the absence of information about what, specifically, a patient no longer competent would want, the *best interest standard* refers to the surrogate's decision making based on collaboration with the patient's physician to determine what would be in the patient's best interest (American Thoracic Society, 1991). This type of decision is used only when the patient's wishes and values are not known. Decisions about the patient's best interest can be reached by weighing the benefits of the treatment against its burdens to the patient. "If the benefits....exceed the burdens, the therapy should be administered. If the burdens exceed the benefits, the therapy should be forgone" (American Thoracic Society, 1991, p. 480).

Effective surrogate decision making relies on prior communication between

patients and their surrogates regarding the patients' specific health care wishes. Empirical research supports the notion that there is insufficient communication between patients and their surrogates. Studies have shown that the majority of patients have not discussed their specific wishes regarding life-sustaining therapies with their family members (Uhlmann, Pearlman, & Cain, 1988). In the absence of such prior discussions, Gutheil and Appelbaum (1983) described surrogate decision making as a "complicated form of guesswork." Emanuel and Emanuel (1992) reported that when a patient becomes incompetent, family members' predictions of the patient's preferences are "not much better than random chance" (p. 2069). Such studies say little about the role and influence of physicians in putting into effect advance directives.

Though the PSDA's enactment did increase interest in documentation of advance directives, the prevalence of formal ADs in many nursing and long-term care facilities is relatively low.

Patient Expectations:

What do patients expect when they formulate an advance directive? Patients who execute advance directives do so to ensure that by documenting their wishes they "will avoid medical torment" (Lynn, 1991). Well-publicized court cases have heightened public awareness of the subject of advanced medical technology and the potential of extending existence, through life-sustaining procedures, almost indefinitely. In a 1988 poll conducted

by the American Medical Association of the general public, 85 percent of the participants trusted their physicians to follow their wishes as expressed in their living will (Ely, Peters, Zweig, Elder, & Schneider, 1992). Though the PSDA's enactment did increase interest in documentation of advance directives, the prevalence of formal ADs in many nursing and long-term care facilities is relatively low. Studies report rates of usage from 4 percent to less than 25 percent. Rates do seem to be rising, however. (High, 1993, p. 498) One fundamental problem with most state laws which permit advance directives is that they make no provision for discussion of such important matters between patients and physicians. (Perlin, 1992)

Advance Directives in Ohio:

Ohio's present advance directives law went into effect on October 10, 1991. A Modification of the 1985 Uniform Rights of the Terminally Ill Act, the Ohio law has its own set of definitions and responsibilities contained in a lengthy (and complicated) piece of legislation. It provides for both Living Will and Durable Power of Attorney for Health Care options. The law also permits the termination of life-sustaining treatment when no advance directive has been signed. In such a case, the family may request termination of treatment when the patient is terminally ill or in a permanently unconscious state (PUS). However, there are many encumbrances to proceeding in the absence of a formal AD, including a twelve-month waiting period if the patient is in PUS. Discontinuation of nutrition and hydration for such patients must be ordered by a county probate court. (Mitrovich, 1992)

Doctors are "out of the loop" unless they wish to enter it.

Ohio physicians have had several years in which to utilize advance directives. Many, if not most, doctors in the state are familiar with the provisions of the law. The Ohio State Medical Association, and other professional societies (such as the Ohio Academy of Family Physicians) have provided educational materials to members and to patients/families about advance directives. Still, there is no reason to believe that doctors routinely talk with patients about living wills or DPOAHCs. As the law stands at present, a person may complete an AD without ever discussing the matter with her physician. Doctors are "out of the loop" unless they wish to enter it.

Ideally, completing advanced directives should be accomplished during adulthood and revised periodically as one's health status and personal goals evolve over a lifetime. Yet we know that, in most states, no more than one-fifth of eligible adults have completed an advance directive. (Sugarman, 1994) Institutional and home settings also have a significant influence on how older persons make such determinations. How such choices are presented to patients or clients seems to be very influential. (Malloy et al., 1992; Mazur and Merz, 1994)

A clear policy element of the Ohio advance directives law was to provide an opportunity for citizens to exercise their autonomy in stating treatment or non-treatment options *before* capacity to make such decisions was lost. Once a patient is in the acute care hospital, important determinations must be made -- e.g., about

intensive care (intubation; artificial hydration and nutrition; medication). In the absence of an AD, others must make surmises or use a "best interest" (objective) standard in making medical decisions. The Ohio law intends for persons to guide such decision-making prior to such acute illnesses. One study notes that even two weeks prior to acute care hospitalization, most persons were capable of advance discussions about treatment options. Once hospitalization occurs, however, distraction, distress or stress (and, of course, loss of cognitive capacity) may render such discussions impossible. (Wenger et al., 1994)

It is, therefore, important for patients to discuss ADs with primary care physicians and others long before acute care hospitalization.

It is, therefore, important for patients to discuss ADs with primary care physicians and others long before acute care hospitalization. The long-term care setting is an apt place for such discussions. Earlier, the outpatient clinic or office setting is appropriate. Designing ways in which to facilitate these sometimes sensitive discussions between patient and physician is the challenge of this project.

Findings

The Patient-Doctor Connection:

When a patient can no longer state her treatment (or non-treatment) preferences, physicians still are obliged to provide care. Such patients are likely to be acutely ill, in hospitals, or chronically ill and without decisional capacity, in long-term care settings. Without specific guidance, doctors apparently have "poor insight into their patients' wishes and may even project their own values...." (Virmani, 1994, p. 909). It would seem apparent that, in the light of such data, physicians would want to participate actively in advance planning. Yet physician reluctance to discuss ADs appears to be the rule. Five barriers to physician-initiated discussions have been noted: time constraints; compensation concerns; discomfort with the subject; beliefs about appropriateness; and lack of understanding. The latter two factors seem particularly strong impediments to doctor-initiated AD discussions. (Morrison, 1994)

Older patients report positive emotional responses when doctors initiate AD discussions.

Talking about death and dying is never an easy task, for patients or doctors. Accurate information is essential, however, if AD determinations are to be made effectively. Healthy, elderly outpatients have demonstrated their abilities to comprehend AD-related information, including accurate

understanding of state laws. Distinguishing between living wills and DPOAHCs has proven more difficult as has been patient understanding of medical procedures such as cardiopulmonary resuscitation. (Moore et al., 1994) Interestingly, younger and better educated patients have the best basic knowledge of ADs. Older patients report positive emotional responses when doctors initiate AD discussions. Such discussions are received most positively by patients who are in good psychological and physical health initiated in the context of an established doctor-patient relationship. (Smucker et al., 1993) Equally important, understanding of ADs clearly improves the more time a physician spends with the patient in focussed discussions.

From the physician perspective, the availability of an AD is a useful guidepost when important -- often life or death -- decisions must be made.

Virtually all studies show that both patients and physicians have positive attitudes towards ADs. From the patient perspective, the goal of ADs is to extend autonomy into the future by projecting one's wishes when they can no longer be expressed. From the physician perspective, the availability of an AD is a useful guidepost when important -- often life or death -- decisions must be made. Why, then, are ADs so infrequently completed and utilized?

From the doctors' perspective:

- Physicians typically initiate discussions when death is near and

decisions, e.g., about cardiopulmonary resuscitation, must be made. This creates problems for all parties, including families. In-hospital situations rarely provide a chance for reflection and intimate discussion.

- Many physicians believe that patients are upset by discussions which deal with death or dying. In one study, more than half the doctors thought that patients would be adversely affected.
- Physicians often state that older patients, with more severe illness, are appropriate candidates for AD discussions. An apparent impetus for initiating discussions appears to be clinical exigencies, e.g., onset of a life-threatening complication. Physician assessments about whether a patient should be resuscitated or not plays a significant role in the timing of AD discussions.

From the patient viewpoint:

- In general, patients want to talk about treatment or non-treatment issues. Many welcome such discussions and want to talk about such questions as likelihood of meaningful recovery.
- Despite such interest, patients tend to be passive in their relationships with physicians and this "silent majority" will respond to -- even hope for -- physician initiated discussions. They cite physician failure as the most common barrier to implementation of ADs.
- The appropriate timing and setting for AD discussions remains an

unresolved question. Patients in hospitals, nursing homes, and outpatient clinics all express a desire to deal with these issues. Still, no more than one-fifth of adults in any given U.S. state have completed an AD. (Reilly et al., 1994)

Education, communication, and supportive understanding are also required.

Re-forming the System:

There is, obviously, no single way to increase use of ADs or to improve the methods in which they are put into action. "Reality" is too complicated for that. For example, elderly persons (in nursing homes and senior citizens' centers) who have executed an AD have been compared with those who have not completed the form. Mere completion does not guarantee that a surrogate decision-maker (usually a family member) is any more aware of the older person's wishes than had an AD never been filled out. Education, communication, and supportive understanding are also required.

Still, health care facilities -- including many long-term care facilities -- have attempted systematic educational campaigns to increase AD use. A large HMO (with more than 100,000 members), for example, undertook a major project to educate patients and medical staff about the advantages and use of ADs. The organization developed easy-to-read materials; included a one-page flyer in its new-member packets; mandated a 3-hour training session for medical staff, with slides and discussion outline; and held staff and member forums on ADs. Members

who attended the forums did appear encouraged to fill out ADs, according to an early audit. Yet more than three-fourths of HMO members remain without ADs. It is perhaps too early to measure the impact of such a sustained program on patient-doctor dialogue. (Houseman, 1994)

In another innovative effort, a home health care agency developed classes specifically designed to encourage staff to inform clients about ADs. Emphasizing ethical issues -- such as the need for thorough informed consent -- the agency organized teaching, documentation and quality assurance functions into a unified program. Outcomes are not yet reported. There is no mention of the role of physicians in the program. (Holly, 1993)

A very elaborate, interdisciplinary intervention designed to increase frail elders' (all participants over age 65) use of ADs was developed in a geriatric evaluation and management clinic. Participants underwent 2-4 months of outpatient treatment at the clinic and were seen by a faculty geriatrician, two geriatrics fellows, a clinical nurse specialist, and a social worker. In a structured interview, the social worker provided basic information; follow-up dialogues were scheduled for later appointments. Patients were offered three options: to record preferences and instructions; to name a proxy; or a combination of the two. Seventy percent of patients recorded ADs; 96 percent named proxies, all of whom were adult children; 83 percent recorded specific treatment preferences. (Luptak, abstract, 1994). Of course, the population studied was quite specific: older persons referred to a geriatric clinic.

In intensive discussions with three focus groups of Ohio primary care physicians, analysis and assessment of ADs was investigated. The doctors represented both university-based and private-setting practices. All physicians had experience with older patients; all but one had participated in AD discussions with patients and, when appropriate, with family members. All had been involved in determinations to withhold or withdraw life-sustaining treatments. The findings of these focus group discussions, with selected statements by physician participants, follow:

1. In general, the primary care physicians who participated in the groups were knowledgeable about advance directives and felt comfortable in discussing them with patients and families.

"I didn't learn about advance directives in medical school. But I've had many chances in the last few years to work on them with patients. It certainly helps to have a living will or DPOAHC in the chart."

2. Discussions occurred in ambulatory, in-patient, and long term-care settings. Most physicians acknowledged that "sooner" was better than later but that commonly these discussions do not occur until in-patient admission or a dramatic change in-patient status.

"It's hard to get younger people interested in planning for such problems. Often, it's only when someone gets really sick that we can talk about advance directives. Then, it may be too late."

3. Some physicians try to discuss advance directives with all of their adult patients, usually during a sequence of office visits. Many however, concentrate on older patients and/or patients with multiple medical problems and feel comfortable in discussing them with patients and families.

"I make discussions of advance directives part of my initial interview with new patients. Then follow-up seems quite routine for the patient and for me."

4. Some physicians have the luxury of having other personnel such as social workers or nurses do the "ground work" about advance directives, thus saving them valuable time.

"At some of the nursing homes where I have patients, they do a good job, usually at admission time, of telling patients and families about their choices. This eases the way for me to have a conversation later on."

5. Physicians report that a discussion about advance directives can be as brief as two to three minutes or as long as one hour. Most agreed that to be effective, ADs must reflect on-going discussion of end-of-life issues, in order to clarify definitions and to educate patients thoroughly. There was general consensus that many patients never demonstrate interest or willingness to fill out the legal forms.

"You can overwhelm patients with information; you can also depress them by talking about death or dying. A few minutes each year, during or after the physical exam, should be sufficient."

6. Physicians reported a variety of roles for family members in the process of obtaining and executing advance directives. Sometimes, families are very involved from the beginning; this seems to make things easier when the time comes for potentially difficult decisions to be made.

"I always start with the patient, but when she or he is uncomfortable talking about ADs, I arrange for a family member to be present at the next appointment. I sometimes ask that family member about his or her plans. This can ease a tense situation."

7. Most of the primary care physicians interviewed had had some experience with the implementation of advance directives and reported that this usually goes smoothly if matters have been discussed openly with the family ahead of time. Sometimes there are problems with the interpretation of what the patient intended.

"You try to get patients to think specifically about what might happen to them in the future. But most people don't know about the real medical complications. I try to get them to tell me, generally, what they would or would not want. If we can air this openly in plenty of time, most family members are cooperative."

8. In order for an AD to go into effect, patients must have lost their capacity to make autonomous decisions. These physicians had a varying degree of comfort with the determination of decisional capacity. Many primary care physicians make this determination independently; others rely on the

opinions of their colleagues in psychiatry and neurology for assistance in this determination.

"You don't need a specialist to see if a patient can understand you. Many patients are, obviously 'out of it.' With others, some follow-up usually gets you an impression you need to put ADs into effect."

9. Artificial nutrition and hydration posed no particular problems. Physicians viewed "feeding" issues as medical treatments like many others, e.g., cardiopulmonary resuscitation.

"If death is imminent, or there is no chance of meaningful recovery, then feeding is like other medical treatments such as CPR. I have never had problems with discontinuing such treatments if it is in the patient's best interest or was his or her earlier wish."

10. Many methods are employed by physicians in the event of family discord about advance directives. Most try to use time, family meetings, education, and discussion to help reach consensus.

"Most ethical conflicts regarding ADs are really communications difficulties. I take a 'negotiator's' position and try not to influence anyone. Getting feelings and values on the table is the best first step."

A variety of suggestions for more effective use of advance directives were made by these physicians:

1. Put "discussion of advance directives" on the list of items to be put uniformly in patient charts.

"ADs are as important as noting the patient's blood pressure. Both are likely to change in the future and both require follow-up."

2. Discuss patient wishes with surrogates before problems occur.

"With the patient's permission, we should ask potential surrogates about their concerns, values, or anxieties early on. We need to establish a relationship with people who will have to make life-and-death decisions in the future."

3. Make better use of personnel in long-term care.

"If every nursing home required a discussion about ADs with the patient or family present, we would all save time and energy in the long run. Nurses and social workers need to include doctors in these deliberations. Doctors have to be willing to spend time, without compensation, in this process."

4. Encourage family meetings.

"Primary care physicians in particular need to get comfortable working with the whole family, particularly with elderly patients or those who are vulnerable to life-threatening ailments."

5. Have a "futility" policy -- a protocol which explains conditions under which

treatment is deemed to have no benefit to a patient.

"Doctors should clarify their own values about continuing care when there is no benefit to patients. They should define just where and when an intervention is futile. Then they should make sure patients and families understand this."

6. State legislation should insist that doctors are made aware of advance directives.

"If the law said that ADs would not go into effect until the doctor had been notified about such determinations, this would have two advantages. First, patients would be encouraged to talk with their physicians before completing an AD. Second, even if the patient filled out a living will or DPOAHC independently, doctors would be notified. Then they could initiate a discussion later on, if the patient wanted it."

7. Put advance directives on computer to link all realms of the health care delivery system

"Sometimes a patient falls through the system. A nursing home patient, or a patient at home, with an AD may receive inappropriate care just because the living will is missing or no one calls the surrogate decision-maker. We need better ways of coordinating information."

In a recent survey of research on ADs, the widespread endorsement of advance planning is noted and the variety of medical directives and proxy designations

across the nation is praised. The task of the physician is to devote time, energy, and attentive caring in the solicitation and perfection of ADs. The process of advance planning should entail five steps: 1) Raising the topic and giving information; 2) Facilitating a structured discussion; 3) Completing a statement and recording it; 4) Periodically reviewing and updating the directives; 5) Bringing prior wishes to bear on actual decisions. (Emanuel et al., 1995)

Recommendations

This study concludes that patient-physician dialogue is indispensable in order to maximize the wise use of advance directives. The following policy and professional recommendations, if adopted, will lead to conversations about ADs that should yield improvement in the process of discussing ethical issues at the end-of-life.

- **Individual patients should be informed about their options regarding ADs in ways which go beyond the strict requirements of the PSDA. Handing a patient a brochure or asking a routine question, e.g., upon admission to a hospital, is a minimalist approach. Establishing policies and procedures within institutions which are constantly monitored for effectiveness and quality are more likely to yield results.**

- **Every health care institution and physician office should have an AD plan in effect for distributing information and encouraging discussion about ADs. For doctors, a fundamental element of the AD**

plan would be the incorporation of discussions into initial office visits with consistent and regular follow-up discussions.

- **Primary care physicians have a unique role to play in developing and executing ADs. Their training and continuing education should include curricular and clinical experience in working with ADs. Continuing education programs should build upon this experience.**

- **AD work is inherently interdisciplinary. Physicians should routinely discuss problems and prospects with other representatives on treatment teams, e.g., nurses, social workers, pharmacists, allied health care professionals, administrators.**

- **Making ADs "portable," i. e., either by computer linkage or by microfiche bracelet, will require legislative enabling and, probably on a county by county basis, coordination of health care institutions, emergency medical technician programs and patient advocacy groups.**

- **Legislation mandating either prior discussions with a physician of record or, at the very least, the informing of that physician of the existence of an AD in order for it to become legally effective would encourage physician-patient dialogue about future health care decisions.**

- **National and/or statewide public advertising campaigns in the various media would help to raise the issues of ADs and, indirectly, encourage patient-physician discussions.**

Patient-physician dialogue regarding ADs is an indispensable endeavor. The preceding recommendations are offered in support of the development of a milieu in which the autonomous patient can work creatively with her physician to discuss future contingencies. Patients, families, institutions, and public officials have a vital stake in trying to facilitate this important work.

**TALKING WITH YOUR DOCTOR ABOUT
ADVANCE DIRECTIVES
(LIVING WILL or DURABLE POWER OF ATTORNEY
FOR HEALTH CARE)**

A CHECK LIST

- ___ If you have concerns about how decisions will be made when you are at the end of your life, or when you are unable to decide for yourself, make a short list of questions that are on your mind

- ___ At your next appointment with your doctor, tell the nurse who sees you first that you want to talk about Advance Directives with the doctor

- ___ Ask the doctor if she can give you printed information about Ohio's Living Will and Durable Power of Attorney for Health Care

- ___ Consider asking your doctor one or more of the following questions:
 - Are there specific health problems you see as likely to emerge in the future, given my family and personal medical history?

 - How would my views about advance directives be noted in my personal medical record?

 - How would you feel, personally, about following my wishes as documented in a Living Will, Durable Power of Attorney for Health Care (or both)?

- ___ Ask your doctor: can you explain the various medical treatments -- such as cardiopulmonary resuscitation (CPR), artificial hydration and nutrition (tube feeding) -- which I might want to elect or refuse as I consider Advance Directives?

- ___ Make a request from your physician: can you help me as I complete these Advance Directives?

- ___ Also ask: would it be useful to re-evaluate Advance Directives with you on a regular basis?

References

- American Thoracic Society Bioethics Task Force. (1991). Withholding & withdrawing life-sustaining therapy. *Annals of Internal Medicine*, 115, 478-484.
- Cruzan by Cruzan v. Director, Missouri Department of Health, 110 U.S. 2841 (1990)
- Ely, J. W. Peters, P. G., Zweig, S., Elder, N. & Schneider, F. D. (1992). The physician's decision to use tube feedings: The role of the family, the living will, and the Cruzan decision. *Journal of the American Geriatrics Society*, 40, 471-475.
- Emanuel, L. L. et al. (1995). Advance care planning as a process: Structuring the discussions in practice. *Journal of the American Geriatrics Society*, 43, 440-446.
- Emanuel, E. J. & Emanuel, L. L. (1992). Proxy decision making for incompetent patients: An ethical and empirical analysis. *Journal of the American Medical Association*, 267, 2067-2071.
- Gutheil, T. G., & Appelbaum, P. S. (1983). Substituted judgement, best interest in disguise. *Hastings Center Report* 13, 8-11.
- High, D. M. (1993). Why are elderly people not using advance directives? *Journal of Aging and Health*, 5, 497-515.
- Holly, C. (1993). Advance directives: A program for home healthcare. *Home Healthcare Nurse*, 11, 34-38.
- Houseman, S. H. (1994). Implementation of an advance directives program in an HMO. *HMO Practice*, 8, 30-34.
- In re Quinlan, 355 A.2d 647 (N.J.) cert. denied, 429 U.S. 922 (1976).
- Lo, B. (1990). Assessing decision-making capacity. *Law, Medicine and Health Care*, 18, 193-201.
- Luptak, M. K. & Boulton, C. (1994). A method for increasing elders' use of advance directives. *Gerontologist*, 34, 409-412.
- Lynn, J. (1991). Why I don't have a living will. *Law, Medicine and Health Care*, 19, 1-2.
- Malloy, T. R. et al. (1992). The influence of treatment descriptions on advance medical directive decisions. *Journal of the American Geriatrics Society*, 40, 1255-1260.
- Mazur, D. J. & Merz, J. F. (1993). How the manner of presentation of data influences older patients in determining their treatment. *Journal of the American Geriatrics Society*, 41, 223-228.
- Mitrovich, P. H. (1992). Analysis of Ohio's living will statute. *Ohio Northern University Law Review*, 18, 759-815.
- Moore, K. M. et al. (1994). Elderly outpatients' understanding of a physician-initiated advance directives discussion. *Archives of Family Medicine*, 3, 1057-1063.
- Morrison, R. S et al. (1994). Physician reluctance to discuss advance directives. *Archives of Internal Medicine*, 154, 2311-2318.

OBRA. (1990). *The Patient Self-Determination Act*. The Omnibus Budget Reconciliation Act of 1990, Pub. L. 101-508, ss 4206, 4751, 42 USC sec 1395 cc (f) (1) & 42 USC sec 1396 a (a) (Supp. 1991).

Pellegrino, E. (1992). Ethics. *Journal of the American Medical Association*, 268, 354-355.

Perlin, T. (1992) *Clinical Medical Ethics: Cases in Practice*. Boston: Little, Brown. and Co.

Reilly, B. M. et al. (1994). Can we talk?: Inpatient discussions about advance directives in a community hospital. *Archives of Internal Medicine*, 154, 2299-2308.

Smucker, W. D. et al. (1993). Elderly outpatients respond favorably to a physician-initiated advance directives discussion. *Journal of the American Board of Family Practice*, 6, 473-482.

Sugarman, J. et al. (1994). Catalysts for conversations about advance directives: the influence of physician and patient characteristics. *Journal of Law, Medicine, and Ethics*, 22, 29-35.

Uhlmann, R. F., Pearlman, R. A., & Cain, K. C. (1988). Physicians' and spouses' predictions of elderly patients' resuscitation preferences. *Journal of Gerontology*, 43, M115-M121.

Virmani, J. et al. (1994). Relationship of advance directives to physician-patient communication. *Archives of Internal Medicine*, 154, 909-913.

Wenger, N. S. et al. (1994). Prior capacity of patients' lacking decision making ability early in hospitalization. *Journal of General Internal Medicine*, 9, 539-543.