The Dangers of Directives or the False Security of Forms

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During the past several years, numerous studies have been conducted regarding advance directives (that is, living wills and durable powers of attorney (DPAs) for health care). Studies have examined how many individuals have executed advance directives,[1] who is more likely to execute such directives,[2] and whether factors such as education,[3] income,[4] race,[5] religiosity,[6] or family status[7] affect the likelihood of having executed an advance directive or one's willingness to do so. Studies have also investigated the effectiveness of different educational strategies aimed at increasing the number of individuals who execute these documents.[8] Finally, a number of researchers have looked at the implementation of advance directives (that is, whether they are followed in the institutional setting).[9]

Although we now have a better understanding of some of these issues, one area that has been virtually ignored is the reliability, validity, and overall user friendliness of the advance directive forms themselves, and, in particular, of the statutory advance directive forms. While physicians and bioethicists writing in this area have focused on the process of "advance care planning"[10] and consider the forms as only one part of a continuum of services that must be made available to patients to allow them to express their wishes regarding medical care if they become incapacitated, consumers most often are faced only with the forms and they themselves must decipher them and figure out how to complete them. Little empirical research has been done on the manner in which individuals complete these forms, whether they are internally consistent in their responses, or whether their responses represent their true wishes.

The development of advance directive forms in many states has been the result of state or federal legislation. Public policy has greatly encouraged the execution of advance directives. In December 1991, the federal Patient Self-Determination Act[11] (PSDA) became effective. The PSDA requires that all hospitals, nursing homes, and other Medicare and Medicaid providers ask patients on admission whether they have executed an advance directive. All states now have a law or laws setting out the procedures for executing these documents and the situations in which they apply.

While some states do not have a statutory advance directive form, most do. Virtually all states with a living will or medical directive statute have a statutory form.[12] As regards DPAs, as of January 1996, only twelve of fifty states did not have a statutory DPA form applying to health care.[13] At least nine states have established statutory combined living will and DPA forms or medical treatment directive forms.[14] Although in a few states the forms must be substantially followed, in most with a statutory form, the form is optional—individuals can alter it or use other forms to express their wishes. Even in states where the forms are solely optional, they are widely used by the public and become the "norm" for these documents in the state. As a result, the wording and format of these forms is a matter of importance.

Because the development of the statutory forms occurs in the legislative arena, their content is the result of a political rather than a "scientific" process. The forms are not tested on a random sample of consumers; rather, they are developed in the context of political debate. In some cases, the debate is heated, and significant controversy has arisen over the content of the forms. In many states, the Catholic Church and right-to-life organizations, as well as civil rights and elderly advocates, are vocal participants in this debate.[15] As a result of political compromise, many of

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the forms ultimately passed by the legislatures are not optimal from a consumer perspective. The forms may be difficult to understand and confusing to those attempting to complete them without assistance.

Development of state advance directive forms: survey results

A recent trend in state advance directive forms is to provide individuals with greater choice in selecting the types of medical treatment they would want in various health scenarios. One of the earliest forms of this type—allowing patients multiple treatment options for different health scenarios—was put forth by Emanuel and Emanuel.[16] Despite some criticism of the approach,[17] the trend seems to indicate, in part, a belief that specific disease state or specific therapy advance directive forms allow more choice for consumers and may be more likely followed by physicians.[18]

Although these newer forms provide consumers with greater flexibility than most of the early living will forms, they may also create some confusion among consumers. A recent survey of advance directive statutes in all fifty states found that, as of March 1996, twenty-six states had statutory advance directive forms that allow the person completing the document to choose among specified options regarding treatment—in some states, under various health scenarios. In many cases, the forms allow an individual to initial or check off the option or options that he/she prefers. These states include Alaska, Arizona, Colorado, Connecticut, Georgia, Hawaii, Idaho, Illinois, Indiana, Kentucky, Maine, Maryland, Nevada, New Hampshire, New Mexico, North Carolina, North Dakota, Oklahoma, Oregon, Pennsylvania, South Carolina, South Dakota, Tennessee, Vermont, Washington, and Wisconsin.[19] In some states, these forms are included in living will statutes; in others, they are part of a DPA statute; and in others they are found in new statutes combining elements of both living wills and DPAs.[20] In the latter cases, the forms may be referred to as advance directive forms or health care instruction forms. A few states have more than one form that provides some choice to an individual, typically a DPA *and* a living will or medical directive form.[21] In general, these "multiple choice" forms differ from state to state; no two are exactly alike. They vary in terms of length, complexity, and the number of choices afforded the decision maker. Some are quite straightforward and include only one choice—typically, regarding receipt of artificial nutrition and hydration.[22] Others allow several choices.

All of the multiple choice state forms, except those in Georgia and Illinois, give individuals the option to state explicitly whether they want artificial nutrition and hydration as distinct from other forms of life-sustaining treatment. At least one state allows an individual to choose separately whether he/she wants nutrition *or* hydration.[23] A few state forms make it clear that withholding or withdrawing artificial nutrition and hydration may result in death by starvation or dehydration.[24] Individuals in these jurisdictions must state clearly that they do not want such interventions despite this possibility.[25]

About half of the forms allow the decision maker to state that he/she does or does not want life-sustaining treatment under certain health situations. Other states do not provide a choice. They limit the options regarding medical interventions to situations where the patient is terminally ill[26] or to cases where the patient is terminally ill *or* in a persistent vegetative state (that is, the decision must apply to both conditions).[27] Of those states that give decision makers an option to decide if they want life-sustaining procedures in certain health conditions, most allow the decision maker to state whether they want life-sustaining treatment if they have a terminal condition and to state separately if they want life-sustaining treatment if they are in a persistent vegetative state.[28] Two states, Maryland and Oregon, go beyond these two conditions. In Maryland, the form also allows individuals to choose whether they want life-sustaining treatment if they have an "end stage condition."[29] In Oregon, the instructions to an agent in a DPA allow decision makers to state whether they want "tube feeding" or any other "life support" if they are "close to death," "permanently unconscious," have an "advanced progressive illness," or are experiencing "extraordinary suffering." For each of the interventions (that is, life support or tube feeding), the decision makers have three options: they may choose not to have the intervention, to have the intervention, or to have the intervention only as their physician recommends.[30]

A few states differentiate the types of life-sustaining treatment that one may be offered and allow the decision maker to decide about each one. The state that provides the most options in this regard is Pennsylvania. The Pennsylvania advance directive form allows decision makers to choose whether they want: (1) cardiac resuscitation; (2) mechanical respiration; (3) tube feeding or any other artificial or invasive form of nutrition (food) or hydration (water); (4) blood or blood products; (5) surgery or invasive diagnostic tests; (6) kidney dialysis; and (7) antibiotics if they are "in a terminal condition or in a state of permanent unconsciousness." They may also state whether they want to make an anatomical gift of all or part of their body.[31]

At least twelve states include an option that allows the decision maker to elect to receive all available medical treatment or maximum treatment.[32] (Indiana actually has a separate form called the "Life Prolonging Procedures Declaration," which the decision maker must complete if he/she wants to exercise this option.) The wording of this option differs from state to state, but at least four state statutes (Georgia, Illinois, Nevada, and South Carolina[33]) explicitly state that cost is not to be considered in making this

decision. For example, the South Carolina form allows a decision maker to choose the following option:

> DIRECTIVE FOR MAXIMUM TREATMENT. I want my life to be prolonged to the greatest extent possible within the standards of accepted medical practice, without regard to my condition, the chances I have for recovery, or the cost of the procedures.[34]

Three states, Maine, Maryland, and New Mexico,[35] allow the decision maker to state a preference regarding pain medication. Other forms discuss pain medication but do not provide this option; they assume the decision maker would want pain medication under all conditions.

In addition to these recent revisions to state advance directive forms, in 1993, the National Conference of Commissioners on Uniform State Laws finalized a Uniform Health Care Decisions Act,[36] which includes model health care instructions. These instructions also allow an individual to make choices regarding life-sustaining treatment, artificial nutrition and hydration, and pain medication. The model instructions appear in Table 1. Advance directive forms in Maine and New Mexico are based on the model health care instructions in the Uniform Act.[37]

Ability of individuals to complete accurately statutory advance directive forms

While the newer forms provide citizens both with more flexibility than the earlier advance directive forms and with the ability to choose among various health care options, the wording of the forms may create confusion for the public, especially if completed without assistance. To determine how well individuals are able to complete a statutory advance directive form that allows them a variety of choices, we asked a random sample of elderly outpatients in the Baltimore metropolitan area to complete the Maryland statutory advance directive form. We then assessed whether they completed that form in a manner consistent with prior verbal expression of their desires and whether they were internally consistent in their completion of the form. The state of Maryland was selected because it was one of the first states to adopt a statutory form with multiple choices for the decision maker.

Development of the Maryland advance directive form

The Maryland advance directive form is included in the Maryland Health Care Decisions Act,[38] which became effective on October 1, 1993. The act covers advance directives and surrogate decision making for individuals who lack decision making capacity. It includes two suggested forms for the purpose of advance care planning: a living will form and an advance directive form. The living will form allows individuals to state whether they want life-sustaining treatment, artificial nutrition and hydration, or all available treatment if they are terminally ill or in a persistent vegetative state.

The advance directive form has two parts. Part A, called "Appointment of a Health Care Agent," allows individuals to appoint health care agents to make health care decisions for them if they lack decision-making capacity. Part B, called "Health Care Instructions," allows individuals to leave instructions about their medical care if they become incapacitated. With respect to termination of life support, Part B allows drafters to specify whether they want life-sustaining treatment or artificial nutrition and hydration if they have a terminal condition, are in a persistent vegetative state, or have an end-stage condition (a condition caused by injury, disease, or illness, as a result of which the patient has suffered severe and permanent deterioration, indicated by incompetency and complete physical dependence, and for which, to a reasonable degree of medical certainty, treatment of the irreversible condition would be medically inef-

(6) END-OF-LIFE DECISIONS: I direct that my health care providers and others involved in my care to provide, withhold, or withdraw treatment to keep me alive in accordance with the choice I have initialed below:

[ ] (a) I do not want my life to be prolonged if I have an incurable and irreversible condition that will result in my death within a relatively short time, if I become permanently unconscious, or if the likely risks and burdens of continued treatment would outweigh the expected benefits,

OR

[ ] (b) I want my life to be prolonged as long as possible within the limits of generally accepted health care standards regardless of my condition.

(7) ARTIFICIAL NUTRITION AND HYDRATION: If I do not initial the box at the end of this paragraph, artificial nutrition and hydration must be provided, withheld, or withdrawn in accordance with the instructions concerning treatment given in paragraph (6). If I initial the box at the end of this paragraph, artificial nutrition and hydration must be provided regardless of my condition. [ ].

(8) RELIEF FROM PAIN: Except as I state in the following space, I direct that treatment for alleviation of pain or discomfort be provided at all times, even if it hastens my death:

Table 1. Model Health Care Instructions, Uniform Health Care Decisions Act (selected portions).

fective). Alternatively, it allows individuals to specify that they want all available medical treatment "in accordance with accepted health care standards," no matter what their condition. It also allows individuals to specify that they do not want medication to relieve pain and suffering if it would shorten their remaining life. An individual may complete Part A alone, Part B alone, or both parts. A copy of relevant sections of Part B of the statutory form, as initially passed, appears in Table 2.[39]

The inclusion of both forms and the wording on each was the product of political compromise; the forms were tested neither for readability nor for reliability. The inclusion of two forms, a living will form and an advance directive form, is decidedly unique. However, as stated above, the inclusion of a check-off with various options is not unique to Maryland. This aspect of the Maryland form was taken in large part from early drafts of the National Conference of Commissioners on Uniform State Laws's Uniform Health Care Decisions Act[40] and the Veterans Administration's Treatment Preferences Form.[41] The Veterans Administration form appears in Table 3.

While the Maryland form is entirely optional and individuals may write their own document custom-tailored to their own preferences, the forms are widely distributed by the state legislature, Office of Legislative Reference, the Office of the Attorney General, and by some lawyers and health care providers. Initial experience with the forms proved problematic. Anecdotal reports from attorneys whose clients used the forms indicate that a number of individuals completed the form incorrectly. They checked items that are mutually exclusive (for example, stating that they did not want life-sustaining treatment if terminally ill but also stating that they wanted all available medical treatment no matter what their condition). At least one individual stated that the form "invites inconsistency" by instructing one to "initial all those that apply."[42]

Study design and methodology

To assess the user friendliness of the form and the degree to which the form actually conveys a patient's true preferences, we asked a random sample of senior citizens in the

HEALTH CARE INSTRUCTIONS

Please initial those statements you want others to follow in the event you are unable to make health care decisions for yourself.

If I am incapable of making an informed decision regarding my health care, I direct my health care providers to follow my instructions as set forth below. (Initial all those that apply.)

(1) If my death from a terminal condition is imminent, and even if life sustaining procedures are used there is no reasonable expectation of my recovery,

___ I direct that my life not be extended by life sustaining procedures, including the administration of nutrition and hydration artificially.

___ I direct that my life not be extended by life sustaining procedures, except that if I am unable to take food by mouth, I wish to receive nutrition and hydration artificially.

(2) If I am in a persistent vegetative state, that is, if I am not conscious and am not aware of my environment or able to interact with others, and there is no reasonable expectation of my recovery,

___ I direct that my life not be extended by life sustaining procedures, including the administration of nutrition and hydration artificially.

___ I direct that my life not be extended by life sustaining procedures, except that if I am unable to take food by mouth, I wish to receive nutrition and hydration artificially.

(3) If I have an end stage condition, that is, a condition caused by injury, disease, or illness, as a result of which I have suffered severe and permanent deterioration indicated by incompetency and complete physical dependence and for which, to a reasonable degree of medical certainty, treatment of the irreversible condition would be medically ineffective,

___ I direct that my life not be extended by life sustaining procedures, including the administration of nutrition and hydration artificially.

___ I direct that my life not be extended by life sustaining procedures, except that if I am unable to take food by mouth, I wish to receive nutrition and hydration artificially.

(4) I direct that no matter what my condition, medication not be given to me to relieve pain and suffering, if it would shorten my remaining life.

___

(5) I direct that no matter what my condition, I be given all available medical treatment in accordance with accepted health care standards.

___

Table 2. Maryland Advance Directive Form (Part B).

city of Baltimore and Baltimore County to complete the form. The study sample base was chosen from senior citizens who were on patient lists at a geriatric clinic in downtown Baltimore, Maryland, or at a private physician practice with offices in Baltimore and in a Baltimore suburb. These two practices were selected in order to reach a variety of individuals with different demographic characteristics.

A random sample of 550 patients was selected from the patient lists of both practices (stratified for gender, age, and source of health insurance, that is, Medicaid or non-Medicaid recipients). To be eligible, the individual had to be living in a noninstitutional setting, be sixty-five years of age or older, and be competent enough to understand and respond to the questions posed. Based on these criteria, 231 persons were found to be eligible for participation (319 could not be located or were deceased, incompetent, or institutionalized).

Trained interviewers contacted these individuals by telephone to arrange an interview. Of the 231, 121 (52 percent) refused to participate. The most common reason given for refusal to participate was an unwillingness to be interviewed by a stranger in their home. In a small number of cases (nine), interviews were conducted by telephone if the individual agreed to be interviewed but not to meet face to face with an interviewer. The total number of interviews completed was 110 (48 percent of the eligible sample). Nonrespondents did not differ significantly from respondents with respect to gender, age, or source of health insurance.

Measurement

The survey instrument consisted of eighty-four questions and took approximately sixty minutes to complete. Respondents were initially asked a series of demographic questions. These were followed by a set of questions on living wills, including awareness of the term and whether they had a living will. An identical set of questions was asked about DPAs. A third set of questions related to preferences for life-sustaining treatment under various scenarios. Respondents were given three scenarios relating to their medical condition and asked whether they would want

I, _____ (print name) intend for this document to guide my health care provider and my health care agent, guardian or representative and for it to be used in conjunction with a living will or durable power of attorney for health care.

Below are listed some situations I may encounter. I recognize these cannot exactly predict what might happen, but I instruct my agent to use this information to the best of his/her ability in making treatment decisions for me and on my behalf.

A. TERMINAL ILLNESS WITHOUT EXPECTATION OF RECOVERY AND PERMANENTLY LACKING DECISION MAKING CAPABILITY.

If the situation should arise in which I am in a terminal condition, am permanently lacking of decision making capability, and there is no reasonable expectation of my recovery, I direct that I be allowed to die a natural death and that my life not be prolonged by extraordinary measures. I do, however, ask that medication be given to me as necessary to relieve pain and suffering, even though this may shorten my remaining life. YES ___ NO ___ INITIALS ___

B. PERMANENT UNCONSCIOUSNESS

Whether or not I am terminally ill, if I become permanently unconscious, I direct that life support be discontinued.
YES ___ NO ___ INITIALS ___

C. BRAIN DAMAGE — UNABLE TO COMMUNICATE

Whether or not I am terminally ill, if I become unconscious and have very little chance of ever recovering consciousness, and would almost certainly be very brain damaged if I did recover consciousness, I direct that life support be discontinued.
YES ___ NO ___ INITIALS ___

D. DOES LIFE SUPPORT INCLUDE FOOD AND FLUIDS?

The above situations (A, B, or C) may occur such that life can be prolonged when food and fluids are provided by tubes or other invasive measures. These include TUBES IN THE NOSE OR STOMACH and INTRAVENOUS FEEDINGS. If one of the above situations develops, I direct that tubes or other invasive measures for providing food and fluids not be started. If they are started, they are to be discontinued in the following situations (see above descriptions):

A. Terminal Illness YES ___ NO ___ INITIALS ___
B. Permanent Unconsciousness YES ___ NO ___ INITIALS ___
C. Brain Damage YES ___ NO ___ INITIALS ___

E. TRIAL OF THERAPY

If I am not terminally ill but recovery is very unlikely (5% or less chance of getting better), I request that a trial of therapy be given as determined by my agent and my physician(s). This therapy may include (but is not limited to) mechanical ventilation, antibiotics, and artificially provided feedings.
YES ___ NO ___ INITIALS ___

Table 3. Veteran's Administration Treatment Preferences Form.

certain types of life-sustaining treatment in that condition. The conditions were:

(1) An incurable illness such as cancer, with only two months to live, pain that affected their ability to function and enjoy life, accompanied by incapacity to make medical decisions.
(2) Permanent unconsciousness with no hope of recovery and no awareness of surroundings, inability to feel pain, but a potential to live for years with life support.
(3) Advanced Alzheimer's disease characterized by an inability to recognize friends or loved ones and total dependency on others for care, with a life expectancy of one or two years.

The life-sustaining treatment interventions they were asked about included:

(1) CPR ("revival if your heart stopped beating").
(2) Ventilatory support ("put on a machine that would breathe for you if you could no longer breathe on your own").
(3) Artificial nutrition and hydration ("tube fed if you could not eat for yourself").

In the final segment of the questionnaire, respondents were given a copy of Part B of the Maryland Advance Directive Form and asked to read and complete it. They were then asked if they had any difficulty understanding the questions and where they thought clarification was needed. To determine external consistency, their responses to the questions on the form were matched with their oral responses to the scenarios. The internal consistency of their responses to the questions on the form was also assessed.

	N	%
Age (mean)	74.7	
Number of children (mean)	2.3	
Gender		
Male		28%
Female		72%
Health Insurance		
Medicaid		7%
Non-Medicaid		93%
Race		
Caucasian		39%
African American		61%
Education		
No more than high school graduate		38%
High school graduate		32%
Some college		17%
College graduate		3%
Graduate education		10%
Occupation		
Human services (child care, etc.)		9%
Homemaker		8%
Blue collar		30%
Clerical		22%
Managerial		5%
Nonhealth care professional		21%
Health care professional		6%

Table 4. Demographic Characteristics of Respondents (N=110).

Analysis

Data were tabulated in the form of frequencies and percentages for demographic variables, knowledge and attitudes about advance directives, and external and internal inconsistencies in the completion of the advance directive form. To determine whether differences were significant between certain groups in terms of inconsistencies in the completion of the form, bivariate comparisons were made with chi-square tests of differences with respect to age, sex, gender, level of education, professional status, race, and if an individual had previously completed an advance directive form.

Survey results

Demographic information

Table 4 displays the demographic characteristics of the sample. The sample was predominantly female (72 percent) and African American (61 percent). The average age of the respondents was 74.7 years. In terms of levels of education, 70 percent had no more than a high school education. Thirty-one percent of respondents were professionals or owned or managed a business. Sixty-nine percent were nonprofessionals (blue collar workers, clericals, homemakers, or human services workers).

Advance directives: knowledge and attitudes

Seventy-five percent of respondents had heard the term *living will*; 28 percent had completed one. A smaller proportion (46 percent) had heard the term *durable power of attorney for health care*; 20 percent had completed one. Seventeen percent had completed both a living will and a DPA.

Scenarios

Responses given to questions regarding life support under various scenarios are shown in Table 5. The results indicate no major variation in responses from scenario to scenario or among the three different types of health care interventions. In general, more individuals seemed to want artificial nutrition and hydration than the other forms of life support, but these differences were not statistically significant.

	CPR[b]	Ventilatory Support	AN&H[c]
Terminal/cancer/with a life expectancy of two months/pain			
Yes (definitely or probably)	19%	12%	26%
Not sure	4%	12%	13%
Probably not or definitely not	76%	75%	60%
Permanently unconscious/no hope of recovery/ no pain/could live for years			
Yes (definitely or probably)	16%	12%	20%
Not sure	9%	7%	5%
Probably not or definitely not	74%	79%	74%
Advanced Alzheimer's disease/inability to recognize friends or relatives/total dependence on others for care/life expectancy 1 to 2 years			
Yes (definitely or probably)	17%	14%	18%
Not sure	8%	6%	8%
Probably not or definitely not	73%	79%	72%

Table 5. Desired Level of Life Support for Three Medical Conditions.[a]

[a] *Between 1 and 2 percent of respondents did not answer these questions.*
[b] *CPR refers to cardiopulmonary resuscitation.*
[c] *AN&H refers to artificial nutrition and hydration.*

Completion of advance directive forms

A total of eighty-two subjects responded to this portion of the survey. Telephone interviews (N = 9) were not included in this portion of the study because it was not possible to ask the respondents to complete the form. Also, fifteen individuals refused to complete the form, primarily due to time constraints. In four cases, individuals were unable to complete the form due to an inability to read or a language barrier. A copy of the advance directive form is provided in Table 2.

In response to the first option on the advance directive form, three respondents initialed both responses, thus indicating that they did not want any form of life support if terminally ill *and* that they did not want any form of life support except artificial nutrition and hydration. Although this may indicate some confusion on the part of the respondents, for this study, these answers were coded as if the respondent did not want any type of life-sustaining treatment other than artificial nutrition and hydration. Forty-seven respondents (57 percent) said they would not want any type of life-sustaining procedures administered to them if they were terminally ill. Twenty-three (28 percent) said they would not want any type of life-sustaining procedures other than artificial nutrition and hydration, if terminally ill. The remaining twelve (15 percent) left the option blank. Of the twelve, three said they were uncertain what they wanted. The remaining nine respondents (11 percent) presumably wanted some other type of life support in these circumstances.

In response to the second option on the statutory advance directive form regarding persistent vegetative state, two respondents again initialed both options; again, their responses were counted as rejecting all life-sustaining treatment except artificial nutrition and hydration. Fifty respondents (61 percent) said they would not want any type of life-sustaining procedures given to them if they were in a persistent vegetative state, while twenty (24 percent) said they would want only artificial nutrition and hydration if in this condition. Fifteen percent said they were unsure what they would want or left the question blank.

In response to the third option on the form regarding end-stage condition, four respondents indicated that they did not want any form of life-sustaining treatment or life-sustaining treatment except artificial nutrition and hydration. Again, they were counted as wanting only artificial nutrition and hydration. Fifty-two respondents (63 percent) said they would not want any type of life-sustaining treatment if they had an end-stage condition, while 25 percent said they would only want artificial nutrition and hydration if in such a condition. Twelve percent either were not sure what they would want under those circumstances or did not initial this option, presumably because they wanted some form of life-sustaining treatment under the circumstances. Table 6 summarizes the responses to options one through three.

In response to the fourth option on the statutory form regarding pain medication, one respondent refused to answer the question and two stated that they did not understand it. Of the remaining respondents, 30 percent said they would not want medication given to them to relieve pain and suffering, no matter what their condition, if that medication would shorten their life. Five percent said they were unsure what they would want in these circumstances. The remaining 65 percent did not initial this option, presumably indicating that they wanted pain medication even if it would shorten their life.

In response to the fifth option on the statutory form regarding receipt of all available treatment, one respondent refused to answer the question because she thought it too general and another stated that she did not understand it. Of the remaining respondents, 39 percent said that no matter what their condition, they wanted to be given "all available medical treatment in accordance with accepted health care standards." Four percent said they were unsure how to respond. The remaining 56 percent did not initial this option, indicating that they did not want all available medical treatment under certain conditions.

Finally, respondents were asked if they had any difficulty completing the form, and for each question were asked whether they had any problems or needed clarification. For the first three questions, *approximately 20 percent of*

	Terminal Condition	PVS[a]	End-Stage Condition
Do not want any LST[b]	57%	61%	63%
Do not want any LST except artificial nutrition and hydration	28%	24%	25%
Unsure or No Response	15%	15%	12%

Table 6. Completion of Advance Directive Form (N=82).
[a] *PVS refers to persistent vegetative state.*
[b] *LST refers to life-sustaining treatment.*

respondents had difficulty with each question or needed some clarification. Some of the specific comments made by individuals when asked whether they had any difficulty answering or completing a question are listed below.

Question 1:

- "Differences between first and second choices are not clear to me."
- "Wording is confusing."
- "Trouble with phrasing of second option [that is, nutrition]."
- "Not clear [what] 'no reasonable expectation of recovery' means."

Question 2:

- "Don't know what persistent vegetative state means."
- "Unclear about administration of nutrition and hydration artificially." [The respondent initially chose second option, but, on explanation, emphatically chose the first.]
- "Not clear what kind of treatment they are referring to and not certain what the choices mean."

Question 3:

- "Never heard of end-stage condition; difficulty with second half; what is physical dependency; choices are confusing."

One person admitted that "All questions seem to overlap and are confusing."

Questions 4 and 5:
Questions 4 and 5 presented more problems for respondents. *Approximately one-third* had difficulty with them. In response to the question about pain medication, 36 percent of respondents had problems. Some of the specific comments about these questions are as follow.

Questions 4:

- "Tricky wording; had to reread to make sure I understood."
- "Didn't make sense to me; wording is confusing."
- "Changed my mind after I read it a few times."
- "Does this mean I do or don't want medication?"
- "This doesn't make sense. I think 'shorten' should be 'lengthen'. What are 'accepted standards'?"
- "Didn't understand what the sentence meant—had to read it three times."
- "Wording was confusing; assumes you've been there and know what the options are—difficult to answer."
- "I'm not even going to try to answer that."

One-third of respondents had difficulty with question 5. Specific comments made by respondents are as follow.

Question 5:

- "If possibility of recovery, would say YES. But if no quality of life, would not want life support systems."
- "Confusing—how do we know what the health care standards are?"
- "Does medical treatment in accordance with accepted care standards mean life support?"
- "What are 'accepted standards'?"
- "Doctors may have different opinions on what is accepted."

Internal consistency of responses

Responses were assessed for internal consistency. If consistent, those who said they did not want life-sustaining treatment under the three different scenarios should have also stated, in response to question 5, that they did not want all available medical treatment given to them no matter what their condition. Many respondents were inconsistent in how they answered these questions, as shown in Table 7. In response to question 1, of those who said they did not want any type of life-sustaining treatment if terminally ill *and* who also responded to question 5 (N=45), thirteen (29 percent) said they would want all available medical treatment no matter what their condition. Of those who said they would only want artificial nutrition and hydration if terminally ill (N=23), fifteen (65 percent) said they would want all available medical treatment no matter what their medical condition. Similar figures were evidenced for the other two health scenarios. Overall, *41 percent of persons were inconsistent in their responses.*

External consistency of responses

Responses to options on the statutory form were also compared with responses to the three scenarios included in the

	Number and percentage wanting all available medical treatment no matter what their condition[b]
If terminally ill	
Do not want any LST[c] (N=45)	13 (29%)
Do not want any LST, except AN&H[d] (N=23)	15 (65%)
	28 (41%)
If in PVS[e]	
Do not want any LST (N=48)	15 (31%)
Do not want any LST, except AN&H (N=20)	13 (65%)
	28 (41%)
If have an end-stage condition	
Do not want any LST (N=50)	15 (30%)
Do not want any LST, except AN&H (N=20)	14 (70%)
	29 (41%)

Table 7. Responses Indicating Lack of Internal Consistency (N=82).[a]

[a] Totals do not equal 82 within each scenario because some respondents did not indicate a preference for these options. N for each scenario represents those who expressed that preference and also responded to question 5 (allowing them to state a preference for the receipt of all medical treatment).

[b] Percentage is based on N for that response.

[c] LST refers to life-sustaining treatment.

[d] AN&H refers to artificial nutrition and hydration.

[e] PVS refers to persistent vegetative state.

interview. Responses to the first, second, and third scenarios should have been consistent with responses to the first, second, and third questions, respectively, on the advance directive form.

Advance directive form (Q1): terminal cancer

Of those who said they would not want any form of life-sustaining treatment in response to option one on the advance directive form (involving a terminal condition) (N=47), seven (15 percent) said they would definitely or probably want to be resuscitated if their heart stopped beating and they had terminal cancer; three (6 percent) said they would want to be put on a breathing machine; and seven (15 percent) said they would want to be tube fed. Of those who said they would only want artificial nutrition and hydration if terminally ill on the form (N=23), four (17 percent) said they would want to be revived if their heart stopped; one (4 percent) said he/she would want to be put on a breathing machine if he/she could not breathe for him/herself; and ten (43 percent) said they would want to be tube fed. Forty-three percent also said they would definitely not or probably not want to be tube fed—a direct contradiction.

Advance directive form (Q2): permanent unconsciousness

Of those who said, in response to option two on the advance directive form, that they would not want any form of life support if they were in a persistent vegetative state and who also responded to the scenarios, three of fifty (6 percent) said they would want to be resuscitated if their heart stopped beating when presented with that scenario; two of fifty (4 percent) said they would want to be put on a machine that would breathe for them if they could not do so themselves; and three of fifty (6 percent) said they would want to be tube fed under these circumstances. Of those who said they would not want any type of life-sustaining treatment other than artificial nutrition and hydration if in a persistent vegetative state (on the advance directive form), five of twenty (25 percent) said they would want to be resuscitated if their heart stopped beating and they were permanently unconscious; four of twenty (20 percent) said they would want to be put on a breathing machine if unable to breathe for themselves; and eleven of twenty (55 percent) said they would definitely or probably want to be tube fed. Nine of twenty (45 percent) said they would probably not or definitely not want to be tube fed under this scenario.

Advance directive form (Q3): end-stage condition

Of those who said they would not want any type of life-sustaining treatment if they had an end-stage condition (in response to option three on the advance directive form), six of fifty-two (12 percent) said they would definitely or probably want to be revived if their heart stopped if they were in the advanced stages of Alzheimer's disease; five of fifty-two (10 percent) said they would want to be put on a machine that could breathe for them; and six of fifty-two (12 percent) said they would want to be tube fed. Of those who said they would not want any type of life-sustaining treatment other than artificial nutrition and hydration if they had an end-stage stage condition, seven of twenty (35 percent) said they would want to be resuscitated if their heart stopped beating and they were in the advanced stages of Alzheimer's disease; seven of twenty (35 percent) said they would want to be put on a machine that would breathe for them if they could not breathe for themselves; and ten of twenty (50 percent) said they would want to be tube fed. Nine of twenty (45 percent) said they would definitely or probably not want to be tube fed. These findings are presented in Table 8.

Internal and external consistency: differences among demographic groups

To determine any differences among groups in their inter-

Response on Form	Percentage Wanting Resuscitation	Percentage Wanting Ventilatory Support	Percentage Wanting AN&H[c]	Percentage Wanting No AN&H
	RESPONSE TO SCENARIOS (%)[b]			
Q1		*Scenario 1*		
No LST[d] if terminally ill N = 47	15%	6%	15%	---
Only AN&H if terminally ill N = 23	17%	4%	43%	44%
Q2		*Scenario 2*		
No LST if in PVS[e] N = 50	6%	4%	6%	---
Only AN&H if in PVS N = 20	25%	20%	55%	45%
Q3		*Scenario 3*		
No LST if in end-stage condition N = 52	12%	10%	12%	---
Only AN&H, if in end-stage condition N = 20	35%	35%	50%	45%

Table 8. External Consistency of Responses to Advance Directives (N=82).[a]

[a] *Totals do not equal 82 within each scenario because some respondents did not indicate a preference for these options. N for each response on the form represents those who expressed that preferences and also responded to the questions about the relevant scenario*

[b] *Percentage is based on N for that response.*

[c] *LST refers to life-sustaining treatment.*

[d] *AN&H refers to artificial nutrition and hydration.*

nal and external consistency in completing the advance directive form, groups were compared based on gender; education (not more than high school versus more than high school); occupation (professional or managerial versus nonprofessional); race (African American versus Caucasian); whether the respondent already had a living will or not; and whether the respondent already had a DPA or not. We found no statistically significant differences based on gender, education, occupation, or whether the respondent already had a living will or DPA. The only statistically significant factor was race. However, after controlling for different levels of education, while race maintained its significance relative to both internal and external consistency for respondents with no more than a high school education, it was no longer significant for respondents with more than a high school education. African Americans with less than a high school education were both more likely than whites to be internally inconsistent in their responses (37 percent vs. 5 percent; $P<.005$) and more likely than whites to be externally inconsistent (39 percent vs. 5 percent; $P<.01$). The difference may be a result of variation between the two groups in the level of education below the twelfth grade.

Discussion and implications of findings

Many of those who were asked to complete the Maryland statutory advance directive form made it clear that they were confused by the language of the form. Confusion was also evident from the lack of internal and external consistency in responses to questions on the form. On the form itself, a few individuals said that they wanted no life-sustaining treatment *and* that they wanted no life-sustaining treatment except artificial nutrition and hydration in a given scenario. Many individuals (41 percent) also said they wanted no life-sustaining treatment or only artificial nutrition and hydration for at least one of the specified medical conditions, yet they wanted "all available medical treatment in accordance with accepted health care standards."

This problem of internal inconsistency may be somewhat unique to the Maryland form. The form does not instruct individuals *not* to initial the option in order to receive all available medical treatment if they have also initialed a statement declaring that they do not want life support in a given scenario. In addition, language such as "in accordance with accepted health care standards" may be confusing to many people, for they may believe that withholding life-sustaining treatment from a patient in a persistent vegetative state, for example, is in accordance with accepted health care standards. The readability of the Maryland form may also be above the reading comprehension of many elderly individuals or individuals who are not in the health care field. Other studies have found that

"patient education materials, health questionnaires, and hospital forms are given to patients with little regard for their ability to read these forms."[43]

We also found a lack of external consistency between responses to the scenarios presented and responses to statements on the form. Of those requesting no life-sustaining treatment on the advance directive form, between 4 and 15 percent said they definitely or probably wanted some intervention (resuscitation, ventilator, and artificial nutrition and hydration) in response to the scenarios; for those requesting only artificial nutrition and hydration on the advance directive form, between 4 and 35 percent said they definitely or probably would want additional interventions (resuscitation or ventilator) in response to the scenarios. Of this last group, those requesting only artificial nutrition and hydration on the advance directive form in response to at least one of the three questions, 44 to 45 percent said they definitely or probably did not want artificial nutrition and hydration in response to the scenarios presented.

These findings raise a broader question about the validity and reliability of advance directive forms in general. While some studies have been addressed the stability of patient preferences regarding life-sustaining treatment over time,[44] and how strictly patients want their advance directives followed,[45] almost no attention has been given to the degree to which statutory advance directive forms capture patients' true preferences.

The issue of patient preferences, however, has been given some attention in the literature. Wetle has written that "[i]t is not uncommon for individuals to express preferences or execute living wills that, on their face, are inconsistent and contradictory. This is, in part, attributable to misunderstanding the concepts, but also may result from the complexity of the issues and the fact that few of us have spent any time considering these topics in any detail."[46] Forrow further argues that answers given to close-ended multiple choice questions regarding life-sustaining treatment are inaccurately labeled patient preferences because the wording of any question "matters tremendously" and different answers can result from minor changes in the way a question is posed.[47]

We perceive a number of public policy implications from these findings. In Maryland and other states interested in developing a useful and effective advance directive form, some effort should be made to assess the reliability and validity of any form included in a statute, whether it be an optional or mandatory form. This advice is not limited to statutory forms, but applies to any "model" form that is likely to be widely distributed in a state. In some cases, these "model" forms are developed by the state bar association or attorney general's office.

In addition to this recommendation, states may want to consider requiring that the execution of an advance directive be accompanied by a discussion with a health care provider—physician, nurse, or social worker—familiar with advance directives. This requirement would accomplish at least two objectives: (1) it is likely to increase communication between patients and health care providers about these documents; and (2) it is likely to reduce inconsistencies in the completion of the forms, to allow health care providers to discuss options with patients, and to get better information from patients about their true "preferences." In a letter to the editor of the *Journal of the American Medical Association*, Emanuel, Emanuel, and Orentlicher made a similar suggestion. They recommended that all advance directives include a section "in which the patient's physician acknowledges that he or she has seen the document and has had an opportunity to discuss its content with the patient."[48]

Alternatively, states may want to encourage the completion of DPAs for health care and generally discourage the completion of medical instruction forms. This approach would allow an agent or proxy to make decisions for an incapacitated patient in the context of a real clinical setting.

Conclusion

While public policy has pushed the execution of advance directive forms, some individuals may be exposed to significant risks in completing some of the "standard" advance directive forms. In some cases, the forms are poorly designed and in need of refinement. In others, to be understood, they require an educational level above that of the average citizen. Inconsistencies were discovered in the completion of these forms by individuals who were relatively healthy, community-dwelling, literate volunteers. If the goal is for individuals to complete these forms and to complete them in a way that makes sense and reflects an individual's true preferences, greater efforts need to be expended to design the forms for reliability, validity, and overall user friendliness. Forms used in many states have never been rigorously tested and may be providing patients and health care providers with a false sense of security about their wishes being carried out in case of incapacity. With a poor form and a patient completing it under less than optimal circumstances (that is, unassisted and perhaps at a time when he/she is ill), dangers arise that the form will be filled out either incorrectly or in a way that does not reflect the individual's true preferences. This type of inaccuracy also raises questions about the efficacy and ethics of distributing such forms at senior centers and other public places without providing individuals with assistance in completing the documents.

References

1. G.A. Sachs, C.B. Stocking, and S.H. Miles, "Empowerment of the Older Patient? A Randomized, Controlled Trial to Increase Discussion and Use of Advance Directives," *Journal of the American Geriatric Society*, 40 (1992): 269–73; M. Devor et

al., "Compliance with Social and Safety Recommendations in an Outpatient Comprehensive Geriatric Assessment Program," *Journal of Gerontology*, 49 (1994): M168–M173; and L.L. Emanuel and E.J. Emanuel, "Decisions at the End of Life: Guided by Communities of Patients," *Hastings Center Report*, 23, no. 5 (1993): 6–14.

2. N. Lurie et al., "Attitudes Toward Discussing Life Sustaining Treatments in Extended Care Facility Patients," *Journal of the American Geriatric Society*, 40 (1992): 1205–08; and G. Sachs, "Increasing the Prevalence of Advance Care Planning," *Hastings Center Report*, 24, no. 6 (1994): S13–S16.

3. M.K. Robinson, M.J. DeHaven, and K.A. Koch, "Effects of the Patient Self-Determination Act on Patient Knowledge and Behavior," *Journal of Family Practice*, 37 (1993): 363–68.

4. *Id.*

5. Robinson, DeHaven, and Koch, *supra* note 3; and Times Mirror Center for People and the Press, *Reflections of the Times: The Right to Die* (Washington, D.C.: Times Mirror Center for People and the Press, 1990).

6. *Id.*

7. D. High, "Who Will Make Health Care Decisions for Me When I Can't?," *Journal on Aging and Health*, 2 (1990): 291–309; and J. Cohen-Mansfield et al., "The Decision to Execute a Durable Power of Attorney for Health Care and Preferences Regarding the Utilization of Life Sustaining Treatments in Nursing Home Residents," *Archives of Internal Medicine*, 151 (1991): 289–94.

8. Cohen-Mansfield et al., *supra* note 7; J. Hare and C.C. Nelson, "Will Outpatients Complete Living Wills? A Comparison of Two Interventions," *Journal of General Internal Medicine*, 6 (1991): 41–46; D.M. High, "Advance Directives and the Elderly: A Study of Intervention Strategies to Increase Use," *Gerontologist*, 33 (1993): 342–49; and M.K. Luptak and C. Boult, "A Method for Increasing Elders' Use of Advance Directives," *Gerontologist*, 34 (1994): 409–12.

9. The SUPPORT Principal Investigators, "A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)," *JAMA*, 274 (1995): 1591–98; M. Danis et al., "A Prospective Study of Advance Directives for Life Sustaining Care," *N. Engl. J. Med.*, 324 (1991): 882–88; M. Danis, "Following Advance Directives," *Hastings Center Report*, 24, no. 6 (1994): S21–S23; and R.S. Morrison et al., "The Inaccessibility of Advance Directives on Transfer from Ambulatory to Acute Care Settings," *JAMA*, 274 (1995): 478–82.

10. Sachs, *supra* note 2; and S. Evans and P. Clarke, "Rethinking How We Communicate About Advance Directives: Hidden Errors in Our Assumptions About Planning for Care," in *Communications and the Patient Self-Determination Act: Strategies for Meeting the Educational Mandate; A Resource Guide* (Washington, D.C.: Annenberg Washington Program, 1993): 20–27.

11. Patient Self-Determination Act 42 U.S.C. §§ 1395cc, 1396a (1994).

12. The exceptions are Delaware, New Jersey, and Ohio.

13. ABA Commission on Legal Problems of the Elderly, "Health Care Power of Attorney Legislation as of Jan. 1, 1996" (unpublished document). These states include Colorado, Delaware, Louisiana, Massachusetts, Michigan, New Jersey, South Dakota, Washington, and Wyoming. In addition, Indiana, Ohio, and Tennessee do not have statutory forms but require that a DPA for health care include specified statutory language. See Ind. Code § 16-36-1-14 (1993) (incorporating § 30-5-5-17 by reference); Ohio Rev. Code Ann. § 1337.17 (Baldwin 1993); and Tenn. Code Ann. §§ 34-6-203, -205 (1991 & Supp. 1995).

14. ABA Commission on Legal Problems of the Elderly, *supra* note 13. Ariz. Rev. Stat. Ann. § 36-3224 (Supp. 1995); Fla. Stat. ch. 765.203 (Supp. 1996) (DPA form allows special instructions); Ky. Rev. Stat. Ann. § 311.625 (Baldwin 1995); Me. Rev. Stat. Ann. tit. 18-A, § 5-804 (West Supp. 1995); Md. Code Ann., Health-Gen. § 5-603 (Supp. 1995); N.M. Stat. Ann. § 24-7A-4 (Michie Supp. 1994); Okla. Stat. tit. 63, § 3101.4 (Supp. 1996); Or. Rev. Stat. § 127.531 (Supp. 1994); and Va. Code Ann. § 54.1-2984 (Michie 1994).

15. D.E. Hoffmann, "The Maryland Health Care Decisions Act: Achieving the Right Balance," *Maryland Law Review*, 53 (1994): 1064–130.

16. L.L. Emanuel and E.J. Emanuel, "The Medical Directive: A New Comprehensive Advance Care Document," *JAMA*, 261 (1989): 3288–93. The Medical Directive includes four hypothetical clinical scenarios. For each scenario, twelve possible medical interventions are listed. Thus, someone completing the directive is asked to make forty-eight hypothetical clinical judgments.

17. A.S. Brett, "Limitations of Listing Specific Medical Interventions in Advance Directives," *JAMA*, 266 (1991): 825–28. Brett argues that the selection of medical interventions out of true clinical context is unrealistic and may not accurately convey a person's true wishes.

18. W.R. Mower and L.J. Baraff, "Effect of Type of Directive on Physicians' Therapeutic Decisions," *Archives of Internal Medicine*, 153 (1993): 375–81.

19. Alaska Stat. § 18.12.010 (1994); Ariz. Rev. Stat. Ann. § 36-3224 (Supp. 1995); Colo. Rev. Stat. § 15-18-104 (Supp. 1994); Conn. Gen. Stat. § 19A-575 (Supp. 1995); Ga. Code Ann. § 31-32-3 (Supp. 1995); Haw. Rev. Stat. §§ 551D-2.6, 327D-4 (1993); Idaho Code §§ 39-4504, -4505 (1993); Ill. Ann. Stat. ch. 755, para. 45/4-10 (1991); Ind. Code §§ 16-36-4-10, -11 (1993 & Supp. 1995); Ky. Rev. Stat. Ann. § 311.625 (Baldwin 1995); Me. Rev. Stat. Ann. tit. 18-A, § 5-804 (West Supp. 1995); Md. Code Ann., Health-Gen. § 5-603 (Supp. 1995); Nev. Rev. Stat. §§ 449.610, -.613, -.830 (Supp. 1995); N.H. Rev. Stat. Ann. §§ 137-H:3, -J:15 (Supp. 1995); N.M. Stat. Ann. § 24-7A-4 (Michie Supp. 1995); N.C. Gen. Stat. § 90-321 (1993); N.D. Cent. Code § 23-06.4-03 (Supp. 1995); Okla. Stat. tit. 63, § 3101.4 (Supp. 1996); Or. Rev. Stat. § 127.531 (Supp. 1994); 20 Pa. Cons. Stat. Ann. § 5404 (Supp. 1995); S.C. Code Ann. §§ 44-77-50, 62-5-504 (Law. Co-op. Supp. 1995); S.D. Codified Laws Ann. § 34-12D-3 (1994); Tenn. Code Ann. § 32-11-105 (Supp. 1995); Vt. Stat. Ann. tit. 14, § 3466 (1989); Wash. Rev. Code § 70.122.030 (Supp. 1996); and Wis. Stat. §§ 154.03, 155.30 (Supp. 1995).

20. While most DPAs provide space for individuals to write in specific instructions that they want their agents to follow or that limit their agents' authority, forms that simply provide this type of option were not included in this tally.

21. These states include Hawaii (Haw. Rev. Stat. §§ 551D-2.6, 327D-4 (1993)), Nevada (Nev. Rev. Stat. §§ 449.610, -.613, -.830 (Supp. 1995)), New Hampshire (N.H. Rev. Stat. Ann. §§ 137-H:3, -J:15 (Supp. 1995)), and South Carolina (S.C. Code Ann. §§ 44-77-50, 62-5-504 (Law. Co-op. Supp. 1995)).

22. See Alaska Stat. § 18.12.010 (1994); Colo. Rev. Stat. § 15-18-104 (Supp. 1994); Haw. Rev. Stat. §§ 551D-2.6, 327D-4 (1993); Ind. Code § 16-36-4-10 (Supp. 1995); and Wash. Rev. Code § 70.122.030 (Supp. 1996). The Colorado Declaration as to Medical or Surgical Treatment allows an individual to state the number of days that artificial nourishment is to be provided. Colo. Rev. Stat. § 15-18-104 (Supp. 1994).

23. N.D. Cent. Code § 23-06.4-03 (Supp. 1995).

24. See, for example, Nev. Rev. Stat. §§ 449.610, -.613, -.830 (Supp. 1995).

25. In Nevada, an individual must initial the following statement if he/she wants artificial nutrition or hydration: "Withholding or withdrawal of artificial nutrition and hydration may result in death by starvation or dehydration. Initial this box if you want to receive or continue receiving artificial nutrition and hydration by way of the gastro-intestinal tract after all other treatment is withheld pursuant to this declaration." Nev. Rev. Stat. § 449.610 (Supp. 1995).

26. Terminal illness, however, is defined differently from state to state. See Alaska Stat. § 18.12.010 (1994) (limiting application of form to "incurable or irreversible condition[s] that will cause ... death in a relatively short time"); Colo. Rev. Stat. § 15-18-104 (Supp. 1994) (restricting form's application to injuries, diseases, or illnesses that are "not curable or reversible and which [are] a terminal condition" defined as "an incurable or irreversible condition for which the administration of life-sustaining procedures will serve only to postpone the moment of death."); Ind. Code §§ 16-36-4-10, -11 (1993 & Supp. 1995) (providing for form's use on physician's certification of incurable injury, disease, or injury from which death will occur in a short time); Nev. Rev. Stat. §§ 449.610, -.613 (Supp. 1995) (same, except it does not require physician's certification); N.D. Cent. Code § 23-06.4-03 (Supp. 1995) (requiring two physicians' certification of "incurable or irreversible condition" that "will result in ... imminent death"); and Tenn. Code Ann. § 32-11-105 (Supp. 1995) (limiting form's use to terminal condition, defined as "any disease, illness, injury or condition, including, but not limited to, a coma or persistent vegetative state, sustained by any human being, from which there is no reasonable medical expectation of recovery and which, as a medical probability, will result in the death of such human being, regardless of the use or discontinuance of medical treatment implemented for the purpose of sustaining life, or the life processes.").

27. See Conn. Gen. Stat. § 19a-575 (Supp. 1995); Idaho Code § 39-4504 (1993); Ky. Rev. Stat. Ann. § 311.625 (Baldwin 1995); Me. Rev. Stat. Ann. tit. 18-A, § 5-804 (West Supp. 1995); N.M. Stat. Ann. § 24-7A-4 (Michie Supp. 1995); 20 Pa. Cons. Stat. § 5404 (Supp. 1995); and Wash. Rev. Code § 70.122.030 (Supp. 1996).

28. See Ariz. Rev. Stat. Ann. § 36-3262 (Supp. 1995); Ga. Code Ann. § 31-32-3 (Supp. 1995); N.H. Rev. Stat. Ann. § 137-J:15 (Supp. 1995); N.C. Gen. Stat. § 90-321 (1993); Okla. Stat. tit. 63, § 3101.4 (Supp. 1996); S.C. Code Ann. § 44-77-50 (Law. Co-op. Supp. 1995); and Wis. Stat. § 154.03 (Supp. 1995).

29. Md. Code Ann., Health-Gen. § 5-603 (Supp. 1995).

30. Or. Rev. Stat. § 127.531 (Supp. 1994).

31. 20 Pa. Cons. Stat. § 5404 (Supp. 1995).

32. See Ariz. Rev. Stat. Ann. § 36-3262 (Supp. 1995); Ga. Code Ann. § 31-36-10 (1991); Ill. Ann. Stat. ch. 755, para. 45/4-10 (Smith-Hurd 1991); Ind. Code § 16-36-4-11 (1993); Me. Rev. Stat. Ann. tit. 18-A, § 5-804 (West Supp. 1995); Md. Code Ann., Health-Gen. § 5-603 (Supp. 1995); Nev. Rev. Stat. § 449.830 (Supp. 1995); N.M. Stat. Ann. § 24-7A-4 (Michie Supp. 1995); N.D. Cent. Code § 23-06.4-03 (Supp. 1995); Or. Rev. Stat. § 127.531 (Supp. 1994); S.C. Code Ann. § 62-5-504 (Law. Co-op. Supp. 1995); and S.D. Codified Laws Ann. § 34-12D-3 (1994).

33. See Ga. Code Ann. § 31-36-10 (1991); Ill. Ann. Stat. ch. 755, para. 45/4-10 (Smith-Hurd 1991); Nev. Rev. Stat. § 449.830 (Supp. 1995); and S.C. Code Ann. § 62-5-504 (Law. Co-op. Supp. 1995).

34. S.C. Code Ann. § 62-5-504 (Law. Co-op. Supp. 1995).

35. See Me. Rev. Stat. Ann. tit. 18-A, § 5-804 (West Supp. 1995); Md. Code Ann., Health-Gen. § 5-603 (Supp. 1995); and N.M. Stat. Ann. § 24-7A-4 (Michie Supp. 1995).

36. Uniform Health Care Decisions Act § 1-19, 9 U.L.A. 201 (Supp. 1995).

37. Me. Rev. Stat. Ann. tit. 18-A, § 5-804 (West Supp. 1995); and N.M. Stat. Ann. § 24-7A-4 (Michie Supp. 1995).

38. Md. Code Ann., Health-Gen. § 5-601 to -608 (1993 & Supp. 1995).

39. The form includes space for individuals to write in other instructions as well as how they want their decisions regarding life-sustaining treatment modified if they are pregnant.

In 1994, an inadvertent error was incorporated into the Annual Corrective Bill approved by the Maryland legislature. The bill deleted the provisions of the advance directive form that allow individuals to state a preference regarding pain medication or to state that they want all available medical treatment no matter what their condition. Despite this omission, the form continued to be distributed by the Attorney General's Office and the Office of Legislative Reference as originally passed. In the 1996 legislative session, a corrective bill was passed, returning the form to its pre-1994 status.

40. Uniform Health Care Decisions Act § 4, 9 U.L.A. 207 (Supp. 1995).

41. Veterans Administration Form 10-0137C (Nov. 1991).

42. Memo from Charles Sabatino, ABA Commission on Legal Problems of the Elderly, to Diane E. Hoffmann, Esq., University of Maryland Law School (July 7, 1995).

43. T.C. David et al., "The Gap Between Patient Reading Comprehension and the Readability of Patient Education Materials," *Journal of Family Practice*, 31 (1990): 533–38.

44. L.L. Emanuel et al., "Advance Directives: Stability of Patients' Treatment Choices," *Archives of Internal Medicine*, 154 (1994): 209–18.

45. A. Sehgal et al., "How Strictly Do Dialysis Patients Want Their Advance Directives Followed?," *JAMA*, 267 (1992): 59–63.

46. T. Wetle, "Individual Preferences and Advance Directives," *Hastings Center Report*, 24 (1994): S55–S58.

47. L. Forrow, "The Green Eggs and Ham Phenomena," *Hastings Center Report*, 24 (1994): S29–S32.

48. E.J. Emanuel, L.L. Emanuel, and D. Orentlicher, letter, "Advance Directives," *JAMA*, 266 (1991): 2563.