

What Do Patients Express as Their Preferences in Advance Directives?

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Background: Since the passage of the Patient Self-Determination Act in 1991, there has been interest in urging patients to execute advance directives (ADs) for medical care. There are not much data, however, as to what the ADs that patients execute actually specify. I have investigated the percentage of inpatients and outpatients who are admitted to a community hospital who have executed ADs, and I have tabulated what preferences are actually expressed in the ADs that are in hospital records.

Methods: A questionnaire is filled out by each patient admitted to this hospital, and their response recorded as to whether they have executed an AD. I have tabulated these responses for inpatients and outpatients for the calendar year 1994. I have also examined the ADs in all available hospital records, and tabulated the wishes expressed in these directives.

Results: For inpatient admissions during the calendar year 1994, of 8727 questionnaires completed, 11% of patients indicated that they had executed an AD. For outpatients, the corresponding figures are 22 966 and 15%. A total of 343 hospital records containing ADs were examined. Of these, 15 were nonmedical directives and were excluded. Of the 328 medical ADs, 86 (26%) were living wills, expressing the wish that if the individual had an incurable disease or irreversible injury that he or she not be given any treatment that would only delay death. There were 210 power of attorney for health care forms

completed; these were 64% of all the medical ADs. Of these, 7 did not specify any preference that patients wanted their proxy to follow. The remaining 203 forms were divided as follows: 189 individuals requested that they did not want life-sustaining treatment if the burdens of treatment outweighed the expected benefits; 12 wanted their lives to be prolonged unless they were in an irreversible coma; and 2 wanted their lives to be prolonged to the greatest possible extent regardless of the chances for recovery or the cost. There were 32 do not resuscitate forms executed exclusively by residents of nursing homes that specified that they did not want cardiopulmonary resuscitation or artificial feeding.

Conclusions: The overwhelming desire expressed by the patients in the ADs was not to have their lives prolonged if their medical condition were such that treatment would merely delay death. Only a minuscule number of patients, less than 0.7%, wanted everything done to prolong life regardless of the chance for improvement or the cost. Because such a small percentage of patients have ADs, it is recommended that each hospital appoint a committee on ADs to do everything possible to encourage patients to execute an AD. A second mission of this committee would be to do everything possible to encourage physicians to pay close attention to their patients' wishes for medical care at the end of life.

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SINCE THE passage by the federal government of the Patient Self-Determination Act,¹ which became effective in December 1991, each hospital, nursing facility, home health care agency, and provider of home care is required to provide information to all new patients regarding their right under state law to make decisions about their medical care. Since that time patients have been encouraged to execute advance directives (ADs), either as a living will (LW) or a power of attorney for health care (PAHC), or minimally, directions for "do not resuscitate" (DNR) and similar specific directions. In Illinois, standard forms are available for both LW and PAHC^{2,3} and are widely used.

Although there are controversies about the actual way such directives are to be fol-

lowed,^{4,5} there appears to be a consensus that they are valuable in promoting the wish of many patients to be allowed to die with dignity and reasonably free of pain when

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further medical treatments and procedures can be of no benefit. There is also a further consequence of reducing the cost of medical care in terminally ill patients when such costs represent no conceivable benefit to the patient. It has been estimated that 27% of the total Medicare budget is consumed by medical costs at the end of life.⁶

Unfortunately, the percentage of patients who actually execute ADs is disappointingly low,⁷⁻⁹ and equally disappointing is the failure of many physicians to honor

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METHODS

A survey was made of all inpatient and outpatient admissions to the hospital in 1 year, 1994, in which patients were asked if they had an AD and responded to the question.

In this hospital all ADs are placed in an individual folder with a red label, so they can be easily identified in a patient's record. Some ADs are executed by individuals who have never been treated in this hospital, in anticipation of future hospitalizations. These individuals are given a patient number and the file is kept with other patient records.

I examined all the ADs available, and tabulated them according to their nature: LW, PAHC option 1, PAHC option 2, PAHC option 3, and DNR. I also recorded details of ADs that did not fit into any of these categories.

these directives, as the reports of the SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment) group¹⁰ clearly demonstrate. The SUPPORT group reported a multihospital program of having specially trained nurses keep physicians aware of ADs and other wishes of their patients in regard to their treatment. The information provided by these nurses appeared to have little impact on the physicians. The authors speculated that having a special group of physicians rather than nurses might have been more effective. Various attempts have been made to inform patients more aggressively about the advantage to them of expressing their wishes, with some limited success reported.¹¹⁻¹⁵ In some situations the physician and hospital are unaware that the patient had executed an AD.

A question arises as to how patients perceive their concerns about their terminal illness, and what they actually specify in their ADs. This article addresses 2 issues: first, what percentage of patients who are admitted to a hospital as an inpatient or outpatient actually have an AD? and second, what do they actually specify in their AD? This article addresses the first question by a survey of inpatient and outpatient admissions to a moderate-sized community hospital in a suburb near Chicago, Ill, and the second question by a survey of all available ADs in this hospital. Although the hospital is situated in a middle-class and upper middle-class community, it draws patients from a much wider area that includes working class and lower middle-class economic groups.

In Illinois, there are, as mentioned, standard forms for both LW and PAHC. The essential part of the LW form² is excerpted here:

If at any time I should have an incurable and irreversible injury, disease or illness judged to be a terminal condition by my attending physician who has personally examined me, and has determined that my death is imminent except for death delaying procedures, I direct that such procedures which would only prolong the death process be withheld or withdrawn, and that I be permitted to die naturally with only the administration of medicine, sustenance, or the performance of any medical procedure deemed necessary by my attending physician to provide me with comfort care.

In the absence of my ability to give directions regarding the use of such death delaying procedures, it is my intention that this declaration be honored by my family and physician as the final expression of my legal right to refuse medical or surgical treatment and accept the consequences from such refusal.

The Illinois Statutory Short Form Power of Attorney for Health Care³ provides for the appointment of the attorney to act on behalf of the patient subject to any conditions specified and then lists 3 options to express their specific wishes, only 1 of which is to be initialed. These options are as follows:

- PAHC option 1: I do not want my life prolonged nor do I want life-sustaining treatment to be provided or continued if my agent believes that the burdens of the treatment outweigh the expected benefits. I want my agent to consider the relief of suffering, the expense involved and the quality as well as the possible extension of life in making decisions concerning life-sustaining treatment.
- PAHC option 2: I want my life to be prolonged and I want life-sustaining treatment to be provided or continued unless I am in a coma which my attending physician believes is irreversible, in accordance with reasonable medical standards at the time of reference. If and when I have suffered irreversible coma, I want life-sustaining treatment to be withheld or discontinued.
- PAHC option 3: I want my life to be prolonged to the greatest extent possible without regard to my condition, the chances I have for recovery or the cost of the procedures.

A third form, initiated at various nursing homes, specifies DNR and other specific wishes. A typical form includes the following:

Guidelines for Life-Sustaining Measures

	Be Used to Sustain Life
Heart resuscitation-CPR	SHALL___SHALL NOT___
Electric shock or mechanical ventilation	SHALL___SHALL NOT___
Tube feedings (nasogastric or gastrostomy)	SHALL___SHALL NOT___

,where CPR indicates cardiopulmonary resuscitation.

RESULTS

The questionnaires filled out by inpatients and outpatients on admission to the hospital during 1994 revealed the following: 15% of 22 966 outpatients and 11% of 8727 inpatients acknowledged having an AD.

A total of 343 patient records with an AD were examined. Of these, 12 (6%) directives were concerned only with financial matters, 2 (1%) with appointment of a guardian, and 1 with permission by a court for emergency treatment; these directives were therefore not considered, leaving 328 records with a medical AD.

There were 86 LWs; 84 used the Illinois standard form. There was 1 nonstandard form that was essentially the same as the standard form. There was 1 Jewish LW, specifying that the exact details of a terminal illness were to be handled "according to Jewish tradition" with consultation with the patient's rabbi. Three of the standard forms had additional written DNR instructions.

A total of 210 of the ADs were PAHC standard Illinois forms, with 4 exceptions, which went into more detail. Seventy-eight of the 210 forms also had standard form LWs attached; since the PAHC is more explicit, these LWs

were consolidated with other PAHCs. Of the 210, 7 did not specify any options, apparently leaving the details up to the appointed attorney. Of the remaining 203, PAHC option 1, specifying no life-sustaining measures, was initiated by 185, and in the 4 nonstandard forms, this option was clearly expressed, totaling 189. The PAHC option 2, specifying that only if the patient is in a coma were no life-sustaining measures to be used, was initiated by 12. The PAHC option 3, specifying that everything possible should be done to prolong life, was initiated by 2.

There were 32 directives that specified options for DNR and artificial nutrition; often "use medications to relieve pain" was written by hand. These were all patients who had been transferred from a nursing facility to the hospital, and had used forms provided by the staff of the nursing facility. All forms contained clearly stated DNR instructions or words to that effect.

CONCLUSIONS

The overwhelming desires expressed by the patients in the directives were not to have life prolonged if the medical condition were such that there is no hope for a quality life, and to be free of pain. Only 2 directives expressed a wish to have everything done for prolongation of life regardless of prognosis or cost. This is less than 0.7% of all the ADs. It is not known whether these figures can be extrapolated to the entire population of the United States, but it is unlikely that they would be much different. Even a figure of 7%, as opposed to 0.7%, would not change the conclusions expressed. It is clear that the vast majority of the elderly wish a death with dignity and as free of pain as possible, and do not wish to have a life without quality prolonged by artificial means.

Unfortunately, only a fraction of the population, and especially of the elderly population, appear to have ADs for medical care. When they have reached a point in a terminal illness or prolonged vegetative state when they can no longer express their wishes, it usually devolves to the closest relatives to make these decisions. Almost every physician has had the experience of being caught in the middle of disagreeing or unreasonable relatives, and, in the current climate of casual lawsuits, feels compelled to provide expensive, useless care.

The SUPPORT⁹ research indicates that physicians are careless about following patients' wishes, and implies that ADs are not truly effective. Yet the alternative of not having them is insupportable. It is well established that a large portion of lifetime expenditures for medical care occurs during the last year of life, mostly for terminal illness. With Medicare funds expected to run out in a few years, the medical profession should do everything possible to reduce costs without any decrease in the quality of care. The preparation of ADs by all our older population and the following of these directives by physicians will certainly reduce the strain on Medicare funds.

RECOMMENDATIONS

Each hospital in the United States should appoint a committee on ADs. Its functions should be to promote the execution of ADs by all older people in its community via pub-

licity in local newspapers, public meetings, and local radio and television programs; to encourage the filing of ADs with hospitals, family physicians, and relatives, so that they can be quickly and easily accessed when needed; to publicize to its medical staff the importance of their following patients' explicit wishes, whether expressed verbally or by an AD, for ethical as well as cost-saving reasons; to monitor the response of the medical staff in this area; and to seek ways of ensuring that ADs are not ignored. It is possible that having physicians explain to newly admitted patients the reasoning behind ADs and their advantages will be more effective than current explanations by social workers or nurses. Since current statistics are so poor in this regard, it would seem reasonable to try this approach; at least 1 hospital has tried this method and found it helpful.¹⁶ Every medical community has a pool of retired physicians, some of whom would probably be glad to reengage themselves as physicians within a hospital setting, with none of the responsibilities of active practice at no cost to the hospital. If this approach is tried, after a period some research could evaluate whether there is an advantage to this method. Retired physicians can also be asked to speak about the advantages of ADs at public meetings.

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The third form the author refers to in the manuscript that specifies DNR and other specific wishes is a typical sample of such forms. In this community, each nursing home has devised its own form. The original source cannot be determined, although they probably originated from DNR forms a long time ago, before passage of the acts legalizing the LW and PAHC.

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