
The Completion of Advance Directives in Primary Care

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Background. The purpose of this study was to determine whether discussion about and distribution of advance directive forms in a rural, private primary health care office would increase the number of patients who complete and return advance directive forms. This study was also designed to identify individual characteristics of patients who complete advance directives compared with those who do not.

Methods. The sample consisted of 195 patients who ranged in age from 21 to 88 years and visited the primary care office during a 1-month period. Patients who met the inclusion criteria were asked to complete a brief questionnaire while waiting to see their primary care provider, either a physician or a nurse practitioner. The survey included questions about education, previous experience with illness, religion, contact with family members, and attitudes concerning death. The primary care provider then briefly discussed with each patient the ad-

vance directive and provided an advance directive form to be completed and returned. The form was short and easy to complete.

Results. The discussion about and distribution of advance directive forms in the primary care office resulted in a 45% return rate. Older patient age ($P=.001$), longer length of time in the practice ($P=.039$), less education ($P=.025$), and physician provider ($r=.002$) were associated with higher completion rates. The variables of provider and level of education were also influenced by older age.

Conclusions. Discussion about and distribution of advance directive forms should be incorporated into primary office care for all adults.

Key words. Advance directive; primary health care; living wills; rural health. (*J Fam Pract* 1996; 42:378-384)

Catastrophic and long-term illnesses often leave individuals and families feeling powerless over their lives. As medical technology progresses, the ability to sustain life artificially increases, sometimes with a concomitant decrease in the quality of a person's life. Technology has its pricetag, and health care financing is a rapidly escalating problem. Cost alone should not determine ethical decisions, but financial considerations are important if technology is used when it is not desired by the patient, when gains are marginal, or when outcomes do not warrant the risks involved. Chambers et al¹ completed a study of total inpatient charges of patients with and without an advance directive during the final hospitalization of their life and found that charges for patients without either a written or

verbal advance directive were more than three times that of patients with an advance directive (\$95,305 vs \$30,478, respectively). This relationship remained statistically significant after controlling for severity of disease, use of an intensive care unit, and number of procedures. The results of this study imply that an enormous cost savings to society may be realized if discussion and decisions concerning advance directives take place.

The Patient Self-Determination Act² (PL 101-508), effective December 1991, responds to problems associated with individuals' inability to make decisions related to life-prolonging medical care. The law requires that all hospitals, nursing homes, health maintenance organizations, hospices, and health care companies that participate in Medicare or Medicaid provide patients with written information on their rights concerning advance directives under state and federal law. They are also required to note refusals of life-prolonging treatment in the medical records.³

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An advance directive is an oral or written statement that informs the health care provider about what forms of medical care an individual would accept or refuse in a specific medical situation.⁴ It also lists the name of a person selected to make health care decisions in the event the patient is unable to express these wishes personally.

It would be more beneficial, not only for patients but for their families and health care providers as well, if patients completed advance directive forms before becoming ill enough to be admitted to a hospital. Before an illness, patients have time to think about their medical care preferences and discuss their wishes with their family or a proxy. Increasingly, it is being suggested that discussions surrounding these issues should be conducted in the primary care setting.^{5,6}

Undertaking this type of discussion is not enthusiastically endorsed by all primary care providers.⁶ Among the concerns providers express is that advance directive counseling may be extremely time-consuming and is not reimbursed by Medicare, Medicaid, or private insurers.⁷ In addition to this dilemma, health care providers, like most members of our society, are often reluctant to discuss issues related to death and dying with either their patients or anyone else.⁷

The research reported here was designed to determine (1) the number and demographic characteristics of patients seen in a private primary health care office during March 1994 who currently had an advance directive in their medical records; (2) whether the discussion of advance directives and distribution of advance directive forms to patients would increase the number of patients who complete and return an advance directive form for their medical file; (3) the demographic characteristics, religion, previous health care experiences, frequency of family communication, and attitudes concerning the acceptance of death of patients who returned the advance directive forms and those who did not; (4) the difference, if any, in the percentage of advance directive forms returned by patients for whom a nurse practitioner was the primary care provider compared with those for whom a physician was the primary care provider.

Methods

Setting

The setting for this study was a private family practice office in a rural Illinois community. The office is currently staffed with a secretary, a licensed practical nurse, a family practice physician, and two part-time nurse practitioners who provide primary care with an average of 350 monthly

visits. Reimbursement for office visits is accepted from Medicare, Medicaid, private insurers, and private self-pay.

Subjects

All returning patients who were at least 21 years of age who did not have a completed advance directive form in their patient record, and who were seen in the office by either the physician or a nurse practitioner during the month of March 1994, were invited to participate in the study. Patients with a developmental delay, dementia, or severe illness were not asked to participate in the study. No patient was enrolled in the study more than once, and no patients being seen in the office for the first time were considered suitable subjects for the study.

Tools

This study used an advance directive form (Appendix) and a questionnaire, both of which were created by the researchers. The questionnaire was designed to determine educational level, marital status, previous experience with illness, religion and attendance of religious services, frequency of contact with immediate family members, and previous questioning regarding identification of advance directive plans of all study participants. Attached to the advance directive form was a brief three-paragraph explanation about advance directives. The purpose of this written explanation was to improve continuity in the study and to minimize the time spent explaining the form. To determine each subject's attitudes toward death, the Death Acceptance dimension of the Life Attitude Profile-Revised (LAP-R)⁸ was included in the questionnaire. The Death Acceptance dimension refers to the absence of fear and anxiety about death and the acceptance of death as a natural aspect of life.

Procedure

At the time patients registered for their scheduled visit, the secretary reviewed their patient record for a completed advance directive form. If none was found, the patient was a candidate for the study, and the consent form, questionnaire, advance directive form, and explanation sheet were placed on the front of the patient record. The nurse invited each patient whose chart showed these forms to participate in the study. Those who agreed to participate were asked to complete the consent form and questionnaire while waiting in the examination room for their primary care provider. The questionnaire took 5 minutes or less to complete and was number-coded to ensure patient confidentiality. Each patient had the op-

portunity to refuse participation in the study by not signing the informed consent form and not completing the questionnaire.

As part of the primary care visit, the primary care provider (either the physician or the nurse practitioner) briefly discussed the purpose and use of advance directives with all patients who were eligible for the study. These patients were then given an advance directive form and explanation sheet, along with an addressed stamped return envelope. Participants were asked to review the information, discuss it with their family or friends, complete the directive, and return it to the office at their earliest convenience. A master guide of study subjects was kept by the office staff. For each subject, it included age and sex, date of the office visit, primary care provider, length of time the patient had been coming to the practice, and date the advance directive form was returned.

Four copies were made of each form returned to the office: two for the patient, one for the hospital where the patient would receive care, and one for the patient's record in the physician's office. The original form was also returned to the patient. A sticker indicating "advance directive on file" was then placed on the front of the chart. Data concerning the number of forms returned were collected until April 30, 1994, 1 month after the last participant was enrolled in the study.

Statistical Analysis

The data obtained from the study were analyzed using the Statistical Package for the Social Sciences (SPSS-PC) program.⁹ The characteristics of the sample, including age, sex, educational level, length of time in the practice, marital status, past experience with illness, religion, and family contact, were summarized with descriptive statistics. The *t* and chi-square statistical tests were used to compare the characteristics of subjects who returned a completed advance directive with those of subjects who did not. Participant responses to questions from the Death Acceptance dimension of the LAP-R⁸ were summed. Because missing data from these questions were infrequent and randomly distributed, the mean value for the dimension in question was inserted as an estimate of the missing value, as suggested by Reker.⁸ The resulting analysis produced a value for each participant's level of acceptance of death. The .05 level of significance was chosen for data analysis. The statistical test of logistic regression was used for multivariate analysis.

Results

Data analysis was completed for 195 patients ranging in age from 21 to 88 years, with an average age of 54 years.

None of the eligible patients refused to participate in the study. During the study period, only three patients already had an advance directive in their medical file and thus were not included in the analysis.

The discussion of advance directives and the distribution of advance directive forms in the primary care office greatly increased the number of patients who completed advance directives for their medical file. A total of 88 (45%) patients had returned a completed advance directive form at the time of data analysis, a large and clinically significant increase over the three that were on file before the study.

Because the average office visit lasts approximately 15 minutes, the researchers considered it important not to introduce new aspects of care that would be time-consuming. Discussion of the advance directive in this study took an extra 3 to 5 minutes at the end of the office visit. This activity was not found to be too time-consuming by any of the providers and did not interfere with the usual office schedule. This aspect of our study contrasts with earlier reports in the literature in which concerns about time consumption during patient encounters were raised.⁷

The only statistically significant differences between the subjects who returned the advance directive form and those who did not were age, length of time in the practice, and level of education (Table 1). Even though these variables were found to be statistically significant, the close proximity between the two groups with respect to these variables had no significant clinical applicability.

The other statistically significant variable found between the two groups was whether the primary health care provider was a physician or nurse practitioner (Table 2). Further analysis also determined that the physician saw older patients (mean age, 57 years) and patients who had been in the practice longer (mean, 28 months). Patients in these groups were more likely to return the form regardless of provider.

Logistic regression analysis was completed to determine the likelihood of the independent variables of age, provider, length of time in the practice, marital status, acceptance of death, having a will, and attendance of religious services altering the dependent variable of returning an advance directive form. These independent variables were chosen because, in univariate analysis, they were either significant or were approaching significance. The results of the logistic regression showed that patient age, length of time in the practice, and type of provider were the three most significant factors affecting the likelihood of an advance directive form being returned. Even though statistical significance was demonstrated, the overall likelihood of predicting who will return an ad-

Table 1. *t* Test Analysis of Study Population Characteristics

Variable	Returned Advance Directive				<i>t</i> Test	P Value
	Yes (n=88)		No (n=107)			
	Mean	SD	Mean	SD		
Age, y	58	16.88	50	17.66	-3.50	.001
Months as patient	28	14.44	24	14.99	-2.08	.039
Education	2.75*	.90	3.04	.87	2.25	.025
Hospitalized past 5 years	1.32	1.69	1.29	1.32	-0.13	NS
Family contact	1.86	1.10	1.77	1.05	-0.59	NS
Attendance of religious services	2.27	1.63	2.67	1.58	1.67	NS
Acceptance of death†	28.40	7.84	26.71	7.26	-1.51	NS

*2=less than 8th-grade education; 3=high school graduate.

†Based on the Death Acceptance dimension of the Life Attitude Profile—Revised, measured on a scale of 6 to 42, on which 42 reflects total acceptance of death.⁸

SD denote standard deviation; NS, not significant.

advance directive form in relation to these factors was low (62%).

Of the 195 study participants, 121 reported experience with hospitalization within the past 5 years. Medical record review indicated that 64 of these subjects had been hospitalized after December 1, 1991, when the Patient Self-Determination Act went into effect. This review was completed to determine the number of people who were informed of advance directives when hospitalized, as specified by law. Of this group, only seven (11%) reported that they had previously been asked to identify their advance directive wishes; it is not known where they were asked this question.

Discussion

Health care providers, like most members of our society, are often reluctant to discuss issues of death and dying.⁷ Despite these concerns, surveys of patients¹⁰⁻¹³ indicate that they would like to have their primary care provider discuss these issues with them while they are still competent and able to make decisions. Even though patient attitude concerning the discussion of end-of-life issues was not elicited in this study, many patients thanked the health care providers for initiating a discussion of this topic. This finding parallels that of other studies.¹⁰⁻¹³ The high return rate of advance directive forms (45%) also may be explained by this positive attitude.

With respect to the impact of discussion about advance directives on the completion of advance directives, the findings of this study coincide with those of three previous studies in the literature.¹³⁻¹⁵ These studies indicate that discussion of advance directives in the outpatient setting significantly increased the number of completed

advance directives returned for the medical record. The difference noted in this study was that the number of advance directives returned (45%) was significantly greater than that found in the studies by Hare and Nelson¹⁵ and Sachs et al,¹⁴ both of which had a 15% return rate; and in the study of Rubin et al,¹³ which had a return rate of 18.5%. This difference raises a question about why the return rate in this study was so much higher than that of the other studies.

The completion rate of advance directives depends in part on three separate yet integrated elements: patient characteristics (eg, age, education), setting characteristics (eg, primary care or hospital), and process characteristics (eg, document description by a trusted health care provider, ease of completion).

The patient characteristics in this study, which were similar to those of other studies in the literature,¹³⁻¹⁵ revealed no clinically significant differences between those who completed an advance directive and those who did not. Therefore, this set of characteristics does not explain the high rate of return of advance directives in this study.

The setting and process characteristics in this study were different from those of the other published studies.¹²⁻¹⁶ The current study was completed in a rural, private primary care office with one physician and two nurse practitioners with whom patients had established rapport because they had received health care from the same providers each time they came to the office. This is in contrast to the urban university settings where the other studies were conducted. In these settings, residents and a variety of physicians provided care. The analysis further emphasizes the importance of setting, in that study participants who had been coming to the practice longer demonstrated a statistically significant ($P=.039$) increase in the

Table 2. Chi-square Data Analysis of the Characteristics of Participants Who Completed Advance Directive Forms (n=88)

Characteristic	Returned % (No.)	P Value
Provider		.002
Nurse practitioner	35 (31)	
Physician	65 (57)	
Sex		NS
Female	61 (54)	
Male	39 (34)	
Marital status		NS
Single	8 (7)	
Married	64 (56)	
Separated/divorced	6 (5)	
Widowed	23 (20)	
Single/married/separated/divorced	77 (68)	.049
Widowed	23 (20)	
ICU experience		NS
Yes	33 (29)	
No	67 (59)	
Experience with terminal illness		NS
Yes	24 (21)	
No	76 (67)	
Religion*		NS
None	4 (3)	
Catholic	38 (32)	
Protestant	59 (50)	
Previously asked to identify advance directive		NS
Yes	13 (11)	
No	88 (77)	
Has will*		NS†
Yes	51 (43)	
No	49 (41)	

*Not all patients answered all questions.

†P=.053.

NOTE: Percentage may not add to 100 because of rounding.

NS denotes not significant; ICU, intensive care unit.

number of advance directive forms returned. This association conflicts with earlier conclusions by Towers,⁷ who stated that a discussion of advance directives ideally should be conducted during the first encounter in the primary care setting.

There is little in the literature about the process characteristics of discussion of advance directives with family members and ease of form completion. The study by Stelter et al¹⁶ identifies family issues and the need for assistance in completing the form as barriers to the completion of a living will. To address these issues, a question regarding the frequency of family contact was incorporated into the questionnaire used in the current study. The majority (87%) of the study population reported that they had daily or weekly contact with family members not

living with them, which is typical in a small rural area and may be partially responsible for the high return rate of advance directive forms. The advance directive form developed for this study (Appendix) was also short and easy to follow, which may have further contributed to the high return rate demonstrated.

The authors of this study feel that the high return rate of advance directives in this study was directly related to the primary care setting in which it was conducted, the long-term relationship between the patients and the health care provider, and the simple, easy-to-complete advance directive form. One limitation of this study is that it was conducted in only one rural primary care office with one family physician and two family nurse practitioners. This limits the generalizability of the findings to other settings.

This study was designed and completed to have clinical applicability for the authors. We have found that it is extremely valuable to discuss advance directives with patients and have them complete the form used in this study before they have a life-threatening illness. For patients who are still able to make decisions when such an illness occurs, it is now much easier to review their preferences listed on their advance directive forms and follow their wishes. With patients unable to make decisions for themselves, completed advance directive forms clearly indicate who should serve as surrogate decision-makers. In many cases in which we have been involved, family members have expressed relief and gratitude that the patient discussed with them and completed an advance directive before the emotional time when making decisions on behalf of the patient became necessary. Having advance directive forms on file is also useful when health care providers in our practice are taking call for each other. Since not all of us know each patient in the practice, we can quickly refer to the advance directive file and discuss end-of-life decisions with greater ease. Most importantly, we feel that our patients are truly receiving the type of care they prefer at the end of their lives.

Conclusions

We found that discussing and distributing advance directive forms in the primary care office significantly increased the number of patients completing advance directives, without increasing the amount of provider time spent at each visit, and that older people who had a longer relationship with their primary care provider were more likely than others to complete advance directives.

Based on these findings, we recommend that in primary care practices, advance directives be discussed with all adult patients and that short, easy-to-use forms be

distributed for that purpose. The promise of advance directives is the promotion of patient autonomy and the more humane use of life-sustaining treatment. This study reveals that discussing advance directives with primary care patients and providing them with forms to complete for their medical records is a practical means of ensuring that patients' wishes regarding end-of-life decisions are fulfilled.

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Appendix

ADVANCE DIRECTIVE FOR CARE AT THE END OF LIFE

I, _____, on this ___ day of _____, 19___, request the following care in the event that my primary health care provider determines my condition (be it injury, disease or illness) is terminal, incurable and irreversible and that death is imminent:

(Indicate Yes or No for Each Item.)

Cardiopulmonary Resuscitation (CPR)	___ Yes ___ No
Use of a Breathing Machine (Ventilator or Respirator)	___ Yes ___ No
Administration of Medications Other Than Those Necessary to Prevent Infection, Provide Comfort or Control Pain	___ Yes ___ No
Blood Transfusion	___ Yes ___ No
Food and Food Substances Through a Catheter or Feeding Tube	___ Yes ___ No

If I am unable to make decisions for myself, I would like the following person(s) to make necessary decisions on my behalf:

1. Name: _____ Relationship: _____
 Address: _____

 Phone (Home): _____ (Work): _____

2. Name: _____ Relationship: _____
 Address: _____

 Phone (Home): _____ (Work): _____

There will be a time when I will want my health care provider to stop keeping me alive. I have provided this information in the hope that it will be easier to respect my wishes about my medical care at a time when I am unable to express them.

Patient: _____

Date: _____

Birthdate: _____

Witness: _____

Date: _____