
Effects of the Patient Self-Determination Act on Patient Knowledge and Behavior

Mary K. Robinson, MD; Mark J. DeHaven, PhD; and Kathryn A. Koch, MD
Jacksonville, Florida

Background. In effect since 1991, the Patient Self-Determination Act (PSDA) requires that institutions receiving government insurance payments document that they have informed patients of their right to decide on life-preserving measures. Implementing the PSDA should make discussion of advance directives a routine part of acute care hospital admissions. Yet the proportion of those actually completing advance directives such as living wills remains relatively small.

Methods. A telephone survey questionnaire was administered to patients who were hospitalized before and after the implementation of the PSDA. Survey questions probed patient knowledge about living wills and behavior toward obtaining living wills.

Results. Patient knowledge about advance medical directives correlated positively with race (white), income (\geq \$10K), and level of education (high school or more). Moreover, a significantly greater number of pa-

tients hospitalized after implementation of the PSDA knew about living wills than the number of those hospitalized before the Act's implementation. However, actually obtaining a living will correlated positively with age (>36 years) alone, and implementation of the PSDA was not related to the number of patients who obtained a living will.

Conclusions. Although the study results show that the measures the hospital in the study used to meet PSDA requirements increased patient awareness of living wills, they failed to increase the number of patients who act on this awareness. This finding indicates that simply informing patients about their right of self-determination is insufficient to meet the intended goals of the legislation.

Key words. Living wills; patient care planning; patient education; patient compliance. (*J Fam Pract* 1993; 37:363-368)

The Supreme Court decision in the case of *Cruzan v Director, Missouri Department of Health*¹ has focused national attention on the issue of decision-making for the maintenance or withdrawal of life-sustaining treatments when a person is unable to make those decisions. In the *Cruzan* case, the Supreme Court upheld Missouri's authority to require clear and convincing evidence to determine an incompetent person's wishes regarding life-sustaining treatments.¹⁻⁴

Supported by the Supreme Court decision on *Cruzan*, the Patient Self-Determination Act (PSDA)⁵

went into effect on December 1, 1991. The PSDA requires institutions receiving government insurance payments to document that they have informed patients of their right to decide on life-sustaining measures. These institutions must also provide education for staff and patients regarding advance directives, which may include a living will, a designation of health-care surrogate, or a medical durable power of attorney, depending on state legislation. Finally, the patient's record must document whether an advance directive has been executed, and there must be no discrimination in medical treatment based on whether a patient has executed an advance directive.⁶

The expected result of implementing the PSDA was to bring discussion of advance directives into the daily routine of acute care hospital admissions.⁷ Medical ethicists have long promoted routine exposure of the public

Submitted, revised, July 7, 1993.

From the Departments of Community Health and Family Medicine (M.K.R., M.J.D.), and Internal Medicine (K.A.K.), University of Florida, Jacksonville. Requests for reprints should be addressed to Mark J. DeHaven, PhD, Family Practice Residency Program, 1255 Lila St, Jacksonville, FL 32208.

to information about such documents. Yet varying levels of familiarity with advance directives persist among both medical personnel and the public.⁸⁻¹¹ Even though living wills have long been promoted by organized groups, the proportion of those actually completing living wills remains relatively small.¹²⁻¹⁷

The aim of the present study was to investigate institutional compliance with the PSDA by examining the Act's effects on patient knowledge and behavior. Successful implementation of the PSDA should generate two measurable results. First, patients' knowledge about advance directives should increase if they were hospitalized after the PSDA was implemented. Second, patient behavior should be affected by the PSDA. Theoretically, patients discharged from the hospital after the PSDA was implemented should be more inclined toward obtaining and signing a living will.

Methods

To comply with the PSDA, the University Medical Center in Jacksonville, Florida, administers a short questionnaire to patients at the time of hospital admission. All patients 18 years of age or older are asked whether they have executed a living will or advance directive, and whether they have designated a surrogate decision maker for their health care under Florida's Durable Power of Attorney law. If patients respond in the affirmative to either question, they are asked an additional question about the location of the actual document. The availability or absence of either of these documents is noted on their admission form. Those patients who do not have either document are provided with a pamphlet on patient self-determination developed by one of the authors and the hospital ethics committee.

For the present study, a survey instrument was designed to examine the effect of the hospital's procedure on patient knowledge and behavior. The purpose of the survey was to gather information from hospitalized patients after their release to determine whether they knew what a living will was, and whether they had completed a living will. We hypothesized that patients released after the PSDA became effective would be more likely to know what a living will was than patients who had been hospitalized and released before that time. Similarly, we expected that patients hospitalized after implementation of the legislation would be more likely to have completed a living will.

Sampling consisted of randomly choosing a 2-month period in 1992 and generating a list of all patients released from the hospital during that period. The period selected was April through May. After all patients under

the age of 18 years were deleted from the list, a systematic random sample was selected. The first respondent was selected at random, and a selection interval (n) was then used to select every n th respondent. This procedure was then repeated for April and May of 1991. When combined, the resulting sample had the properties of a random sample, stratified on the basis of when a patient was released, either before or after implementation of the PSDA. Sample estimates are accurate to within ± 5 percentage points at the 95% confidence level.¹⁸

Pretests were conducted to identify problems with the survey instrument and to determine sample size and the likely completion rate for attempted interviews. In the pretest, as in the actual survey, four attempts were made to contact respondents before they were dropped from the study.

Characteristics of the target population also contributed to sample size considerations. The patient population tends to be slightly more nonwhite than white, predominantly female, and low income.¹⁹ Because fewer subjects are needed to get an accurate sample from a relatively homogeneous and familiar population, it was not necessary to gather information on an inflated number of respondents.²⁰

Based on the findings of previous studies at our institution, we postulated that attitudes and behaviors might be related to patient demographic characteristics.²¹ Thus, in order to examine the relation between patient characteristics and knowledge and behavior concerning living wills and the PSDA, a number of analyses were performed. The analyses used chi-square tests for independence among categorical variables. In cases where sample sizes were small and expected cell frequencies were less than five, Fisher's exact test was used.¹⁸ The median age of 36 years was used as the cutoff to create the dichotomous variable for age; t tests were used to test for the differences in means when age was treated as a continuous variable.

Logistic regression was used to examine the independent effect of each predictor variable while controlling for the effects of the other variables.²² This technique was used to estimate the effects of the set of independent variables on the probability that an individual (1) knew what a living will is, and (2) had obtained and signed a living will. Only respondents with complete data were used in the analyses.

Results

Those who were hospitalized before and those who were hospitalized after the PSDA was implemented were similar in most respects (Table 1). The disproportionate

Table 1. Characteristics of Respondents Hospitalized Before and After Implementation of the Patient Self-Determination Act

Variable	Sample	
	Pre-PSDA, % (n = 188)	Post-PSDA, % (n = 184)
Age (y)		
18-36	46.8	50.5
>36	53.2	49.5
Sex		
Female	71.3	75.0
Male	28.7	25.0
Race		
Nonwhite	53.2	50.0
White	46.8	50.0
Income (\$)		
<10,000	64.4	69.0
≥10,000	35.6	31.0
Education		
<HS	43.1	45.1
HS+	56.9	54.9

NOTE: There are no significant differences between the sample distributions at $P \leq .05$. PSDA denotes Patient Self-Determination Act; HS, high school.

representation of women and low-income patients is consistent with previous research on the same population.¹⁹ University Medical Center is centrally located in a low-income area, and the overrepresentation of women results from the number of maternity patients admitted and released during the study period.

To assess the effects of the PSDA on patient attitudes and behavior, patients were asked numerous questions about living wills and terminal care decisions. All respondents were asked if they knew what a living will was, if they had a living will, how they would like to be treated if terminally ill, and other similar types of questions. The 25-item questionnaire also asked the post-PSDA respondents specific questions designed to evaluate the effectiveness of the hospital's procedure for complying with the PSDA. The present analysis focuses on whether respondents reported knowing what a living will was and whether they reported having obtained a living will.

The data from the two groups were analyzed separately to examine their comparability with regard to demographic factors that might have influenced patients' views and actions about living wills.⁶ The results of these bivariate analyses are shown in Tables 2 and 3.

The results reported in Table 2 indicate that knowledge of living wills is significantly related to a respondent's race, income, and level of education. In both the pre- and post-PSDA samples, whites were significantly more likely than nonwhites to know what a living will was, as were those with at least a high school education when compared with those with less than a high school education ($P \leq .01$). Similarly, there were dramatic dif-

Table 2. Percentage of Each Sample Responding Yes to the Question "Do you know what a living will is?" by Respondent Characteristics

Variable	Sample	
	Pre-PSDA (n = 188)	Post-PSDA (n = 184)
Age (y)		
18-36	36.4	43.0
>36	39.0	55.0
Sex		
Female	38.8	52.9
Male	35.2	37.0
Race*		
Nonwhite	26.0	38.0
White	51.1	59.8
Income* (\$)		
<10,000	30.6	42.5
≥10,000	50.7	63.2
Education*		
<HS	27.2	36.1
HS+	45.8	59.4

* $P \leq .01$ in both samples.

PSDA denotes Patient Self-Determination Act; HS, high school.

ferences between the two income levels, with significantly more of those in the high-income category knowing what a living will was, compared with those in the low-income category ($P \leq .01$).

To test the effects of the PSDA, whether a respondent was in the pre- or post-PSDA sample was cross-tabulated with whether they knew what a living will was. Those hospitalized after PSDA implementation were sig-

Table 3. Percentage of Each Sample Who Both Knew What a Living Will Was and Responded Yes to the Question "Have you obtained and signed a living will?" by Respondent Characteristics

Variable	Sample	
	Pre-PSDA (n = 71)	Post-PSDA (n = 90)
Age* (y)		
18-36	00.0	2.4
>36	25.6	16.3
Sex		
Female	9.6	8.2
Male	26.3	17.6
Race		
Nonwhite	3.8	5.9
White	20.0	12.5
Income (\$)		
<10,000	16.2	9.4
≥10,000	11.8	10.8
Education		
<HS	8.7	13.3
HS+	16.7	8.3

* $P \leq .01$ in the Pre-PSDA sample.

PSDA denotes Patient Self-Determination Act; HS, high school.

nificantly more likely to be aware of living wills than those hospitalized before implementation ($P \leq .05$). Among the former group, 48% knew what a living will was, compared with only 37% of those in the latter group.

The relation between respondent characteristics and whether a respondent had obtained and signed a living will is shown in Table 3. This survey item was asked of only those respondents who knew what a living will was. The results reveal that unlike knowledge of living wills, behavior was significantly related to age alone. Among the pre-PSDA sample, 61 of 71 (89%) patients had not obtained or signed a living will. All of those who responded that they had done so were in the older age group ($P \leq .01$). Indeed, the mean age of those who had obtained a living will was 61.1 years, compared with a mean age of 43.0 years for those who had not obtained a living will ($P \leq .01$).

Among those surveyed after implementation of the PSDA, no statistically significant relationships were found in the categorical analysis. Although the percentage of those in the older age group who had obtained living wills (16%) was larger than those in the younger age group (2%) who had done so, the relationship was not significant. When age was treated as a continuous variable, however, significant differences were found between those who had obtained a living will and those who had not. The mean age of those in the former group was 58.8 years, compared with a mean age of 40 years for those in the latter group ($P \leq .01$).

Whether patients were hospitalized and released before or after implementation of the PSDA had no statistically significant effect on whether they had obtained and signed a living will. Of those hospitalized before, 14% (10 of 71) had obtained and signed a living will, compared with 11% (9 of 81) of those who were hospitalized after the Act's implementation.

Although the bivariate findings demonstrated that the PSDA was significantly related to respondent knowledge of living wills, it is not clear whether this variable affected patient knowledge independent of the other effects. The following analyses examine this relationship using all patients as a combined sample, when controlling for the influence of other patient characteristics. In these analyses, age is measured as an interval-level variable. The results from these estimations are shown in Table 4.

The effects of patient characteristics on having knowledge of a living will are shown in model 1 of Table 4. All of the independent variables were significant. Non-whites were less likely than whites to have knowledge of living wills; and being female, older, better educated, and having higher income significantly increased the probability of knowing what a living will was. Finally, when

Table 4. Effects of Respondent Characteristics on Knowledge of Living Wills and Whether a Respondent Has a Living Will, Controlling for the Effects of Other Variables (Combined Sample)

Variable	"Do you know what a living will is?"	"Have you obtained and signed a living will?"
	Model 1 Estimate	Model 2 Estimate
Race (nonwhite)	-0.92*	-0.99
Education (HS+)	1.06*	0.45
Age	0.03*	0.06*
Income \geq \$10,000	0.72*	0.35
Sex (female)	0.70†	-0.66
PSDA (after implementation)	0.64*	-0.09

* $P \leq .01$.

† $P \leq .05$.

HS denotes high school; PSDA, Patient Self-Determination Act.

the effects of all other variables were controlled, patients hospitalized after implementation of the PSDA were significantly more likely than those hospitalized before implementation to be aware of living wills.

The effects of the same set of independent variables on the likelihood that a respondent had obtained and signed a living will are shown in model 2 of Table 4. The results of this specification indicate that age was the only significant predictor of this variable. The positive relationship indicated that when controlling for all of the other factors examined, older patients were more likely than younger patients to act on the information that the PSDA intended to disseminate.

Discussion

The present study suggests that to some extent the PSDA increased patient knowledge regarding advance directives. There was considerable variation, however, concerning who was successfully informed. Our multivariate analysis revealed, for example, that having knowledge of advance directives varied significantly with a patient's race, sex, age, education level, and income. Moreover, implementation of the PSDA did not alter patient behavior. This variable had no demonstrable effect on the likelihood that patients had obtained and signed a living will.

Other investigators have conducted similar surveys of a variety of populations with regard to advance care directives and have found results similar to those reported here. A statewide survey of a general population of adults in Kentucky, for example, revealed that 37% of the state's residents knew about their state's law concerning living wills and 9% had completed a living will.¹² In our study, 37.8% of the pre-PSDA group knew about

living wills, and 14.0% had completed one. Our pre-PSDA group was, therefore, very similar in knowledge and behavior to residents of Kentucky.

In another study of knowledge of advance directives in Maryland, investigators conducted a telephone interview of elderly homebound patients and their caregivers.¹³ Those without advance directives were questioned whether they knew what a will, a living will, and a durable power of attorney were. About one third of those surveyed knew about living wills; again, that percentage is consistent with our pre-PSDA group's knowledge. However, only 5% of those surveyed had completed a living will. In a similar survey administered to 75 ambulatory elderly by personal interview, 52% of the subjects said they were familiar with living wills, but none had signed a living will, and only 3% had discussed a living will with their physician.¹⁴

In a third study, a larger number of patients were surveyed in New England. Consistent with our findings, that survey demonstrated that 57% of the outpatients wanted a living will, but only 7% had obtained and signed one.¹⁵

No other study has yet examined the impact of the PSDA on patient knowledge and behavior. Clearly, implementation of the PSDA by the hospital studied has had a positive impact on patient knowledge, but no demonstrable effect on behavior. A significantly larger number of respondents claimed to know about living wills after rather than before implementation of the PSDA, which suggests that the hospital is successfully educating a substantial number of patients. On the other hand, slightly fewer than one half of those hospitalized after the PSDA could recall being given information about advance directives.

A number of explanations can be suggested for why only about one half of those surveyed after the PSDA recall being given information. Generally, people who are admitted to the hospital are in acute pain, such as maternity patients who are in labor or those acutely ill with fevers, vomiting, shortness of breath, and other debilitating symptoms. Under such conditions it is difficult to review an extensive informational handout. Further, patients in intensive care units may not receive any information until they recover, assuming the hospital's implementation mechanism is sufficient to ensure receipt at that time.

Patients are given several forms to complete and sign at the time of admission, including consent to be treated, financial responsibility forms, and the information about advance directives. It may be unrealistic to expect all patients to recall the contents of one written document in such a setting. The meaning of such information is likely to have more import for patients who believe they may

need a living will in the foreseeable future, such as elderly patients or patients with chronic or terminal illness. The PSDA requires that information be given to every adult patient, although the degree of relevance would be considerably less for a maternity patient than an oncology patient.

Perhaps a better way of presenting advance directive information would be to give it as part of a discharge package to be read while the impact of having been in the hospital is still fresh but without the distraction of acute symptoms and admission documents. Or, as has been suggested by others, perhaps these discussions are more suited to an outpatient setting.^{23,24} Regardless of the timing or the setting, reinforcement by the patient's primary longitudinal physician may prove to be the most important factor in achieving patient compliance with obtaining and completing an advance medical care directive. Indeed, some suggest that a question about whether a patient has a living will be included as part of a comprehensive patient history.²⁵

This survey demonstrates an inherent fallacy in the apparent intent of the PSDA. Broad distribution of information regarding their legal rights to all patients may be essentially wasted effort and expense. An improved mechanism to target populations in need of advance care documents within the foreseeable future might be more effective. Targeting at-risk patients would require that physicians who care for such patients become educated and committed to these ideas. Enthusiasm within the medical profession for ensuring patient autonomy must be fostered, and the medical profession's tendency toward paternalism further reduced. If physicians can be taught to routinely address these issues—especially when the patient is chronically or terminally ill—within the context of the patient-physician relationship, and within the relative security of physicians' offices or patients' homes, then the purpose of the PSDA may become more effectively realized.

Acknowledgments

This project was supported by a grant from the Department of Community Health and Family Medicine, University Medical Center of the University of Florida College of Medicine, Jacksonville. The authors wish to acknowledge Lisa Duzant for her assistance with data collection, and the reference staff of the Borland Library for research assistance.

References

1. *Cruzan v Director, Missouri Department of Health*, 497 US 261, 110 S Ct 2841 (1990).
2. White BD, Siegler M, Singer PA, Iserson KV. What does Cruzan mean to the practicing physician? *Arch Intern Med* 1991; 151: 925-8.

3. Thomasma DC. The Cruzan decision and medical practice. *Arch Intern Med* 1991; 151:853-4.
4. Doukas DJ, Brody H. After the Cruzan case: the primary care physician and the use of advance directives. *J Am Board Fam Pract* 1992; 5:201-5.
5. Patient Self-Determination Act [1990], Pub L 101-508 §§ 4206, 4751 (OBRA), 42 USC 1395 cc(a) et seq (1990).
6. Koch KA. Patient Self-Determination Act. *J Fla Med Assoc* 1992; 79:240-3.
7. Grant KD. The Patient Self-Determination Act: implications for physicians. *Hosp Pract* 1992; Jan:38-48.
8. Gordon GH, Tolle SW. Discussing life-sustaining treatment. A teaching program for residents. *Arch Intern Med* 1991; 151:567-70.
9. Doukas DJ, Gorenflo DW, Coughlin SS. The living will: a national survey. *Fam Med* 1991; 23:354-6.
10. Brunetti LL, Carperos SD, Westlund RE. Physicians' attitudes towards living wills and cardiopulmonary resuscitation. *J Gen Intern Med* 1991; 6:323-9.
11. Goldstein MK, Vallone RP, Pascoe DC, Winograd CH. Durable power of attorney for health care. Are we ready for it? *West J Med* 1991; 155:263-8.
12. High DM, Turner HB. Are Kentuckians using advance medical directives? *J Ky Med Assoc* 1991; 89:546-51.
13. Daly MP, Sobal J. Advance directives among patients in a house call program. *J Am Board Fam Pract* 1992; 5:11-5.
14. Gamble ER, McDonald PJ, Lichstein PR. Knowledge, attitudes and behavior of elderly persons regarding living wills. *Arch Intern Med* 1991; 151:277-80.
15. Emanuel LL, Barry MJ, Stockle JD, Ettelson LM, Emanuel EJ. Advance directives for medical care—a case for greater use. *N Engl J Med* 1991; 324:889-95.
16. Elder NC, Schneider FD, Sweig SC, Peters PG, Ely JW. Community attitudes and knowledge about advance care directives. *J Am Board Fam Pract* 1992; 5:565-72.
17. LaPuma J, Orentlicher D, Moss RJ. Advance directives on admission: clinical implications and analysis of the Patient Self-Determination Act of 1990. *JAMA* 1991; 266:402-5.
18. Ott RL, Rexroat CA, Larson R, Mendenhall W. *Statistics: a tool for the social sciences*. 5th ed. Boston: PWS Kent, 1992:358-62.
19. Robinson MK, DeHaven MJ, Wallace JB, Fost T. Hypercholesterolemia: case finding in family practice. *South Med J* 1992; 85:1092.
20. Backstrom CH, Hursh-Cesar G. *Survey research*. 2nd ed. New York: John Wiley & Sons, 1981:52-118.
21. Koch KA, Rodoffer HD, Wears RL. Changing patterns of death management in an intensive care unit. *Crit Care Med*. In press.
22. Aldrich JH, Nelson FD. *Linear probability, logit, and probit models*. Beverly Hills, Calif: Sage University Paper Series on Quantitative Applications in the Social Sciences, 1984:9-27.
23. Cotsonas CE. Informed consent: law, clinical reality, and the role of the family physician. *J Am Board Fam Pract* 1992; 5:208-14.
24. Council on Ethical and Judicial Affairs, American Medical Association. Guidelines for the appropriate use of do-not-resuscitate orders. *JAMA* 1991; 265:1868-71.
25. Ventres WB, Spencer SS. Doctor-patient communication about resuscitation: "have you signed an advance directive?" *J Fam Pract* 1991; 33:21-3.