Changes in Advance Care Planning in Nursing Homes Before and After the Patient Self-Determination Act: Report of a 10-State Survey

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OBJECTIVE: The Patient Self-Determination Act (PSDA) implemented in 1991 has focused national attention on the right of patients to be involved in decision-making and on the use of written advance directives. We report changes in advance care planning with the PSDA and other historical events in nursing homes in 10 states.

DESIGN: Pre- and Post-observational cohort study

PATIENTS: Nursing home residents, residing in 270 long-term care facilities in 10 states, stratified to ensure representation of urban and rural facilities in each state. In 1990, 2175 patients were sampled, and 2088 different patients from the same facilities were sampled in 1993. Six-month follow-up was obtained at both time periods.

MAIN OUTCOME MEASURES: Advance care planning was defined as the documentation in the medical record of a living will, a durable power of attorney, a "Do Not Resuscitate" (DNR) order, a "Do Not Hospitalize" (DNH) order, or an order to forgo artificial nutrition or hospitalization.

RESULTS: The rate of chart documentation of living wills increased from 4.2% in 1990 to 13.3% in 1993, and DNR orders increased dramatically from 31.1% to 51.5%. The rates of DNH and orders to forgo artificial hydration and nutrition remained less than 8% in both years. We found striking variations in advance care planing among the 10 states. In 1990, having a DNR order varied from 10.1% to 69.2% across the 10 states. With the exception of Oregon, where 69.2% of patients already had a DNR order, the states saw a 1.5 to 3.1 times increase in the rate of DNR orders in 1993 compared with 1990.

CONCLUSION: With the implementation of the PSDA, there was modest increase in documentation of living wills, but DNH and orders to forgo artificial hydration and nutrition remained the same. There was a substantial increase in DNR orders that began before the PSDA implementation. This increase was associated both with the implementation of the PSDA and the increased debate about the appropriateness of CPR for nursing home residents. This increase varied considerably among geographic areas from the 10 states. Future research is needed to understand this geographic variation. **J Am Geriatr Soc 45:939–944, 1997.**

Health care institutions have increasingly become the site of death for older persons.[1] The majority of these deaths are preceded by a decision to forgo either CPR, other life-sustaining treatment, or hospitalization.[2,3] The courts and professional and consumer organizations have stated that such decisions should be guided by patients' informed preferences and values.[4–9] Written advance directives have been endorsed widely as a means for patients to guide care before a possible future period of decisional incapacity. Yet, the majority of Americans have not written an advance directive,[10–12] and healthcare institutions have rarely collected information about directives even when they are completed.[13]

In December 1991, the Patient Self-Determination Act (PSDA) was implemented to ensure that healthcare institutions, including long-term facilities, recognize and honor patients' written advance directives.[14] At face value, the PSDA requires that persons be informed of their rights under state law to participate in their medical decision making and to complete written advance directives. Additionally, institutions are required to ask whether the patient has a directive, document the existence of the directive in their medical record, and maintain formal written policies about directives. Many have debated the appropriateness of the timing of admission to inform patients about advance directives, the lack of obligations imposed on physicians, and the cost of implementing the PSDA.[15–18]

The PSDA was implemented in face of limited research about advance care planning in long-term care facilities. Previous research had focused mainly on the use of DNR orders.[19–24] One study reported an increase in the rate of DNR orders and limitations of care between 1984 and

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1988.[23] A second study noted increases in the documentation of advance directives in the medical record with the implementation of the PSDA but did not find an increase in DNR orders.[24]

In 1987, Congress mandated that long-term care facilities collect uniform and comprehensive information to assess residents.[25] The use of the comprehensive instrument, the Resident Assessment Instrument (RAI), is required upon admission to the facility and is updated annually as well as when there are significant changes in the resident's condition. As part of this assessment, information is collected on advance care planning, defined as whether the resident has a living will, and/or an order to forgo resuscitation, artificial nutrition and hydration, or hospitalization. A 10-state evaluation was conducted on the impact of the RAI between 1990 and 1993.[26] In this paper, we report the changes in advance care planning that occurred in the 3-year study period and the regional variation in DNR orders before and after the passage of the PSDA.

METHODS

Study Population

Subjects were nursing home residents of facilities participating in an evaluation of the Resident Assessment Instrument mandated by Nursing Home Reform Amendments of the Omnibus Reconciliation Act of 1987. Ten states were selected for variation in reimbursement and staffing patterns. For full discussion of state selection criteria, please see Phillips and colleagues overview of this project.[26] In each of these states, a major Metropolitan Statistical Area (MSA) and adjacent rural counties were selected such that 24 urban and three rural facilities could be readily recruited. From the pool of 316 facilities recruited for participation, 270 facilities participated for a response rate of 85%. In 1990 and 1993, residents were recruited from each facility based on the current census. Depending on the size of the facility, a fixed sample of eight, 12, or 16 residents was sampled.

Data Collection

A nurse with experience in geriatric nursing and employed by the study collected data to complete the RAI based on review of the medical record, conversations with staff, and interactions with residents. The assessment portion of the RAI is the Minimum Data Set (MDS). The MDS collects information on the patients' cognitive, physical, and emotional functioning, well-being, nursing care needs, medical diagnoses, demographic characteristics, and the presence of advance care planning as noted in the medical record. The section on advance care planning collects information on whether patients have any of the following explicitly noted in their medical records: a living will, a Do Not Resuscitate (DNR) order, an order to forgo artificial hydration nutrition, and/or an order to forgo hospitalization. In another section, entitled Responsibility, information about the presence of a durable power of attorney or health care proxy is collected. Identical information was collected from the two samples (1990 and 1993) in the participating facilities. A second assessment was completed approximately 6 months after the initial assessment.

Analysis

Because the sampling design relied on complex, multistage, cluster sampling, we performed all analyses with SUDAAN statistical software to weight cases appropriately and to adjust the standard errors to account for sampling strategy employed in this study.[27] This allowed us to calculate weighted frequencies representing all 58,000 residents in all certified nursing homes in the selected metropolitan and adjacent rural areas of the 10 states. First, we examined the characteristics of those subjects sampled before and after the PSDA using either a chi-square test or Student's *t* test. Second, we examined the weighted frequencies for the indicators of advance care planning before and after the implementation of the PSDA. Third, we examined trends in each of these rates over the four periods of observation (Fall 1990; Spring 1991; Spring 1993; Fall 1993) using the chi-square test for trend. Fourth, we examined differences in the rate of change in DNR orders among the 10 geographical regions. To further understand this regional variation, we examined variation among subjects who were severely cognitively and functionally impaired as defined by the Cognitive Performance Scales,[28] and we performed a multivariate logistic regression analysis on un-weighted data. The latter results showed the same variation even after adjustment for age, sex, type of insurance, and the availability of a family member. Additionally, cognitive and functional status did not reduce this variation. These latter results are available on request. We used a probability level of $P < .05$ to designate statistical significance.

RESULTS

In 1990, 2175 residents in long-term care facilities were sampled, and in 1993, 2088 subjects. These subjects were drawn from a population of more than 58,000 subjects in the 10 states. Before the PSDA implementation, the average age was 81.3, 78% were female, and 16.9% were classified as highly dependent in both ADL function and cognition. In the data collection after the PSDA, a similar cohort was enrolled from these same facilities (see Table 1).

Changes in Advance Care Planning

After implementation of the PSDA, the rate of DNR orders, durable powers of attorney, and living wills increased (see Table 2); however, orders to forgo hospitalization or artificial hydration and nutrition were less than 8% at both time periods. Before the PSDA, only 4.2% of the residents in long-term care facilities were noted to have a living will. This increased to 13.3% post-PSDA ($P < .01$). As shown in Figure 1, the dramatic increase in living wills and durable powers of attorney occurred after the PSDA implementation. DNR orders nearly doubled, with slightly more than one in every two persons having a DNR order (51.5% post-PSDA compared with 30.1% before the PSDA, $P < .01$). Unlike living wills, the increase in DNR orders began at a time before the PSDA implementation (See Figure 1).

As shown in Table 3, the rate of DNR orders and the relative increase associated with the passage of time varied among the geographical regions in the 10 states. At both time points, nearly three-fourths of nursing home residents had a DNR order in Oregon. The remaining geographic regions showed rates of DNR orders increasing between 1.5 and 3.1 times from 1990 to 1993.

The rate of DNR orders among those with severe functional impairment varied similarly in each of the 10 geographical areas (See Table 3).

The geographic regions in each of the states, with the exception of Virginia and California, increased their docu-

Table 1. Characteristics of Residents Enrolled Before and After the Patient Self-Determination Act (PSDA)*

	1990 n = 2175	1993 n = 2088	*P* Value
Mean Age (SD)	81.3 (12.1)	82.3 (11.5)	.02
Gender (%)			.46
Female	78.0	75.6	
Male	22.0	24.4	
Race (%)			.32
White	84.7	85.2	
Black	13.8	13.1	
Other	1.5	1.7	
Marital status (%)			.09
Never married	16.3	17.0	
Married	13.8	14.9	
Widowed	68.9	68.1	
Medical diagnoses (%)			
Dementia	44.7	51.7	.01
Stroke	22.2	24.7	.13
Cancer	5.2	5.7	.71
CHF	17.4	18.5	.29
COPD	10.2	11.4	.46
Function/Cognitive status† (%)			.19
High dependent with severe cognitive impairment	16.9	17.0	
Dependent or high dependent with moderate to severe cognitive impairment	25.3	24.9	
Minimum oversight to extensive assistance with moderate to severe cognitive impairment	17.5	18.9	
Dependent or high dependent with mild to intact cognitive impairment	9.6	9.3	
Minimum oversight to extensive assistance with mild to intact cognitive impairment	30.8	29.9	

* Results are weighted for sampling design of the study. Pre-PSDA the weighted total N is 62,097, and Post-PSDA weighted N is 58,612.
† MDS Cognitive Performance Scale and Functional Impairment Scale created by Morris and Colleagues.[28]

Table 2. Changes in Advance Care Planning Between 1990 (Pre-PSDA) and 1993 (Post-PSDA)

Advance Care Planning	1990 (n = 2096) (%)*	1993 (n = 2047) (%)*	*P* Value
Living Will	4.2	13.3	<.01
Durable Power of Attorney	7.6	19.5	<.01
Do Not Resuscitate order	31.1	51.5	<.01
Order to forgo hospitalization	2.6	4.4	.01
Order to forgo artificial hydration and nutrition	3.1	7.9	<.01

* Results are weighted for sampling design of the study. The 1990 weighted total N is 61,374, the 1993 weighted N is 57,604.

mentation of living wills by a factor between 2.4 and 6.1. The highest rate of living wills in 1993 was found in Des Moines, Iowa, where nearly one in four (22.8%) nursing home residents had documentation of a living will. There was not the same increase in documentation of orders to forgo hospitalization or artificial hydration and nutrition. In 1993, only nursing home residents in Hartford, Connecticut, and Oakland, California, had an order to forgo hospitalization more than 5% of the time. In only four regions did more than one in 10 nursing home residents have an order to forgo artificial hydration and nutrition.

DISCUSSION

For health care providers and residents in long-term care facilities, the PSDA represents one of a series of federal interventions to promote patient autonomy. The PSDA followed other nursing home reforms, passed as part of OBRA 1987, covering the use of psychotropics and restraints. Unlike these other regulations, the PSDA's main impact is on education and enhancing documentation of written advance directives. Healthcare facilities, including long-term care facilities, are required to educate patients on entrance about their right to participate in medical decision-making and to

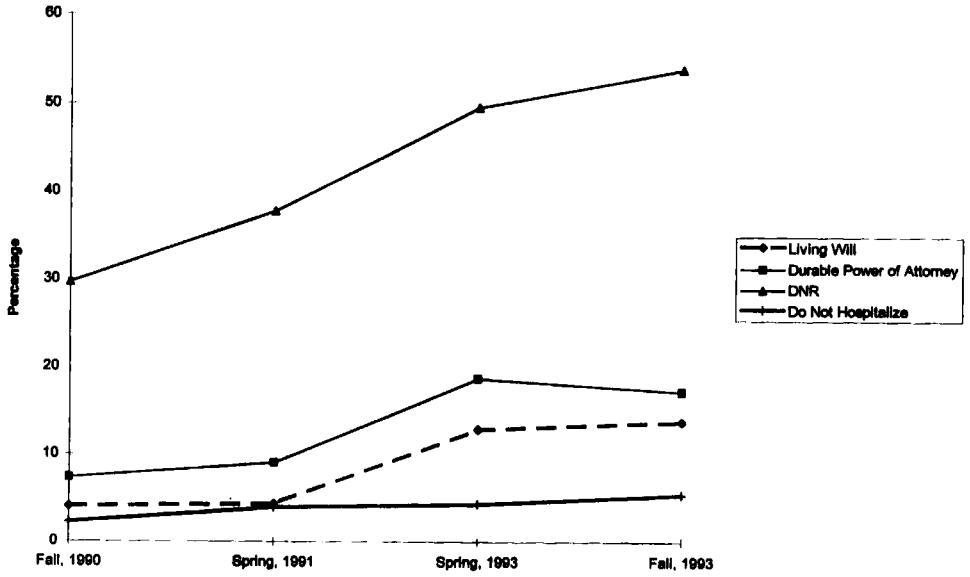

Figure 1. Changes in Advance Care Planning with the increasing debate about appropriateness of resuscitation and the implementation of the Patient Self-Determination Act (January 1991). There was a significant linear trend in the rates of DNR, living wills, and durable power of attorney (i.e., $P < .001$ for a linear trend).

Table 3. Regional Changes in Do Not Resuscitate Orders Between 1990 and 1993

Region	Entire Cohort			Among Those with Severe Functional and Cognitive Impairment*	
	1990 (%)†	1993 (%)	*P*	1990 (%)	1993 (%)
Portland, OR	69.2	70.2	.82	85.2	84.5
Minneapolis/St Paul, MN	48.1	73.9	.01	49.9	91.3
Hartford, CT	28.2	66.5	.01	27.4	75.8
Oakland, CA	38.5	57.3	.01	56.3	71.0
Demoine, IA	30.2	53.4	.01	48.6	63.3
Virginia Beach/Newport News, VA	27.0	45.2	.02	46.0	66.9
Cleveland, OH	21.8	39.9	.01	32.2	47.5
Nashville, TN	26.0	38.5	.02	38.9	51.8
Baltimore, MD	27.0	39.6	.03	35.3	48.9
Dallas, TX	10.1	31.4	.01	29.8	38.7

* As defined by the Cognitive Performance Scale.[28]
† Results are weighted for sampling design of the study.

formulate advance directives. Additionally, institutions must have formal policies about advance directives and document the existence of written directives in medical records. Our research provides early evidence that suggests that the documentation of living wills and durable powers of attorney increased with the passage of time and the implementation of the PSDA; however, the majority of residents did not have formal advance directives. These results are consistent with early impact of the PSDA in acute care hospitals.[29,30] Furthermore, we document an increasing rate of DNR orders that began before the PSDA implementation.

Our results highlights two important concerns about advance care planning and decision making at the end of nursing home residents' lives. Less than one in five residents have a living will or durable power of attorney. These results are consistent with previous research of advance care planning that has shown that the majority of older persons and those who reside in long-term care facilities have not completed a written advance directive.[31–33] Hence, the majority of decisions will need to be made either through an informally named surrogate or by a guardian named by a court of law. A second concern is the striking regional variation in the rate of DNR orders.

In 1993, one in two long-term care residents had a DNR order, a 60% increase over 1990. In part, this represents a substantial change in which the appropriateness of resuscitation is addressed. This change occurred in the setting of increasing scrutiny of the appropriateness of cardiopulmonary resuscitation (CPR) in nursing home residents[34–37] and the implementation of the PSDA. Our research design cannot attribute causality to either of these potential reasons. Additionally, it is quite possible that other unknown historical events could account for these changes in the rate of DNR orders.

While this increase is significant, we found substantial variation in the rate of DNR orders among the 10 geographic areas. In 1993, fewer than 40% of long-term residents in

Texas, Maryland, and Ohio had a DNR order, whereas Oregon, Minnesota, and Connecticut had DNR order rates of nearly 70%. A review of existing state legislation about decision-making does not explain these differences.[38] None of these states has statutes concerning the use of DNR orders. With the exception of Minnesota, all have laws permitting surrogate decision-making. Based on this review of existing statutes, we did not find evidence to suggest that existing state laws account for this regional variation.

We are unable to state whether there are too many DNR orders in Portland or too few in Dallas. However, this variation persists even among a cohort of residents with severe cognitive and functional impairment (see Table 3). Many would classify a resuscitation attempt in this group of individuals as a futile treatment.[36] Future research is needed both to understand the degree to which this increased rate in DNR orders represents an informed process of communication and to understand whether state variation is accounted for by physician practice styles, patient preferences, institutional characteristics, or still other unknown factors.

Besdine has noted that decision making about hospitalization of nursing home residents is a more important concern than resuscitation.[39] We found that after the implementation of the PSDA, less than one in 10 long-term care residents had documentation of orders to forgo hospitalization. Hospitalization is not without risk of iatrogenesis and relocation stress for long-term residents.[40] The risks and benefits of hospitalization of nursing home residents require further research. We urge further empirical research and professional dialogue about the appropriateness of intercurrent hospitalizations.

Our results reflect the early changes in documentation of advance care planning in long-term care facilities with the passage of time and the Patient Self-Determination Act. It is quite possible that the true impact of the PSDA may only be measured a decade from now. The educational effort of the PSDA may not have an early dramatic impact on a population in which the majority of persons have substantial cognitive impairment The PSDA may have increased discussions among patients, health care providers, and families about preferences and values that have not been noted in the medical record. However, a substantial impact in such discussions has *not* been noted in cohorts assembled from the acute care hospitals where data collection has utilized both patient interviews and retrospective reviews of the medical records.[29,30] It should be noted further that patients or their surrogates were not interviewed as part of this effort to evaluate the RAI. It is quite possible that patient preferences may account for the state variation in DNR orders. However, previous research indicates that the majority of older persons do not desire resuscitation and that those who initially prefer resuscitation change that preference when informed of the outcomes of CPR.[41-43]

CONCLUSION

After the implementation of the PSDA, documentation of formal advance directives increased modestly. DNR orders increased dramatically starting about 8 months before the PSDA implementation. However, we have identified a number of areas of concern. The majority of long-term care residents do not have an advance directive, suggesting that healthcare providers will need to rely on surrogate decision making. An order to forgo hospitalization was present in less than one in 10 patients. DNR order use varied substantially among the study areas in the 10 states. This substantial variation suggests the need for increasing consensus and development of guidelines about the appropriateness of resuscitation and hospital transfer for nursing home residents.

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