

Department of Health and Human Services

**OFFICE OF
INSPECTOR GENERAL**

**PATIENT ADVANCE DIRECTIVES:
FACILITY AND PATIENT RESPONSES**



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EXECUTIVE SUMMARY

PURPOSE

To examine the early responses of staff and patients in hospitals, nursing facilities, and home health agencies to the requirements of the Omnibus Budget Reconciliation Act of 1990 advance directive provisions.

BACKGROUND

On November 5, 1990 the Congress enacted advance directive provisions as part of OBRA 1990, which became effective on December 1, 1991. The law's intent was to provide adult patients an opportunity to express their desires about medical treatment in a variety of settings including hospitals, nursing facilities and home health agencies. An additional intent was education of the population on advance directives such as living wills and durable power of attorney for health care.

Concerns have been raised about the impact of the advance directive provisions. Some concerns involve whether the provisions will result in greater involvement of individuals in health care decisions. Additional concerns addressed patient understanding of materials as well as their importance. Finally, concerns were raised that patients could be incorrectly informed of their rights or make unreasoned decisions due to introducing information at admission, often a time of turmoil.

This report is a companion to the report "Patient Advance Directives: Early Implementation Experience." That report found that while most of the sample facilities are complying with the general legislative requirements, there is a lack of clear and consistent documentation in patients' charts. This lack of documentation increases the possibility that patient treatment wishes may not be followed. In addition, the first report found that 21 percent of the patients in hospitals, nursing facilities and home health agencies have advance directives, and that two-thirds of the individuals interviewed from these facilities had some understanding of advance directives.

FACILITY SPECIFIC INFORMATION

While no findings or recommendations are presented in this report, a more detailed discussion is undertaken of the variance in the above findings by facility type: hospital, nursing facility, and home health agency. Within each type of facility patient understanding, documentation, and staff and community education efforts are examined with reference to such items as facility characteristics, patient payment type, and patient characteristics and diagnoses. In addition, implementation problems faced by facilities and their suggestions for meeting requirements and enhancing patient understanding are provided.

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INTRODUCTION

PURPOSE

To examine the early responses of staff and patients in hospitals, nursing facilities, and home health agencies to the requirements of the Omnibus Budget Reconciliation Act of 1990 advance directive provisions.

BACKGROUND

On November 5, 1990 the Congress enacted advance directives provisions as part of OBRA-90. These provisions became effective on December 1, 1991¹. The law's intent was to provide adult patients an opportunity to express their desires about medical treatment in a variety of treatment settings². An additional intent was education of the population on advance directives such as living wills and durable power of attorney for health care³. The legislation required Medicaid/Medicare health care providers to develop written policies and procedures and patient materials addressing directives under State law. Materials were to be presented to patients upon admission to care and documentation was to be placed in the patient's chart stating whether or not he/she had an advance directive. In addition, facilities were to ensure that advance directives were not required to receive treatment. Finally, both staff and community education on advance directives were to be provided by the facility.

Concerns exist about the impact of the advance directive provisions. Based on previous studies there is concern whether the legislation will result in greater patient involvement in health care decisions⁴. There is also concern that patients may not understand materials and their importance^{5,6}. Finally, there is concern that patients may be incorrectly informed of rights, or make unreasoned decisions due to providing information at admission, often a time of turmoil⁷. In order to address these concerns, we conducted a study of the early implementation of the advance directive provisions to examine compliance with the legislative requirements and these concerns.

Data collection was conducted at 72 randomly selected facilities in 12 counties, in six States including urban, suburban and rural, as well as large and small facilities. The data was obtained from staff interviews, written materials and a review of additional documentation and patient charts. Additionally, interviews were conducted with patients or family members who were randomly selected from the charts reviewed.

To provide a context for the information presented in this report, a brief summary of the findings from the previous report are presented.

Most Of The Sample Facilities Are Complying With The General Legislative Requirements. Generally, the facilities have successfully implemented the administrative aspects of the advance directive requirements with hospitals showing the highest level of overall compliance and home health agencies the lowest. The legislative requirement most

frequently unmet was the facility responsibility to provide community education with 32 percent of the facilities failing to have planned or provided such education on the topic.

The Lack Of Clear And Consistent Documentation In Patients' Charts Increases The Possibility Their Treatment Wishes May Not Be Followed. While administrative requirements have generally been met, only 26 percent of the sample facilities had clear documentation of whether the patient did or did not have an advance directive in 100 percent of the charts reviewed. In addition, many facilities did not use consistent methods of documenting in the charts, making it difficult to locate information on directives. Using weighted data projected to the general population reviewed, 19.5 percent of the charts lacked documentation or contained ambiguous statements regarding advance directives. Finally, of the individuals with directives only 60 percent had a copy in their chart.

Twenty-one Percent Of The Patients In Hospitals, Nursing Facilities And Home Health Agencies Have Advance Directives. Examination of the weighted sample data indicates the population included in this inspection had a slightly higher rate of advance directive use than populations reported in the literature. In addition, nursing facility and female patients were more likely to have a directive.

Two-thirds Of The Individuals Interviewed Had Some Understanding Of Advance Directives. Understanding of advance directives among the individuals in the sample was fairly high with 67 percent of the 348 patients or family members interviewed indicating they understood advance directives. Being informed of the right to have a directive appeared to have had some impact on patients, with 21 percent of the individuals interviewed stating they would consider getting a directive after hearing about them and four percent of the individuals actually executing a directive after receiving treatment.

FACILITY SPECIFIC INFORMATION

This report provides an indepth discussion of data collected for a companion report, "Patient Advance Directives: Early Implementation Experience." Discussions are presented by the types of facilities included in the initial inspection, hospitals, nursing facilities and home health agencies. The intent of the information is to provide a point of comparison and examples of methods used by some facilities to meet requirements of the advance directive provisions, which may be used as guidance for others.

We conducted our review according to the *Quality Standards for Inspections* issued by the President's Council on Integrity and Efficiency.

FACILITY REPORTS

HOSPITALS

Sample Characteristics:

- 24 Hospitals
- 591 Charts
- 120 interviews of patient/interested other

Patient Understanding

Patient Understanding Varied by Hospital Characteristics, Payment Type and Documentation Style.

Patient understanding of advance directives varied by type and size of hospital. A greater percentage of for-profit hospital patients demonstrated an understanding of advance directives than those receiving care from non-profit or public hospitals. Patient

Hospital Sample	Patient Understanding
20 For-Profit	75%
95 Non-Profit	62%
5 Public	60%

understanding is somewhat higher in larger hospitals. For example, while 68-70 percent of patients in large hospitals demonstrated understanding about directives, only 62% of patients in hospitals with 100 or fewer beds understood. There was little difference in patient understanding of advance directives between facilities

that discussed information with the patient, provided written information to the patient or referred the patient to another person if they wished to discuss directives.

There were some differences in understanding based on patient payment source. Medicare patients were most likely (75%) to understand advance directives, followed closely by private insurance patients (72%). The lowest understanding of directives was found among Medicaid (18%) and HMO (43%) patients.

The form of provider documentation of advance directives also had some effect on patient understanding. Greater understanding was found among patients whose facilities documented the advance directives on a standard form (65%) versus a note (55%). Likewise, patients whose personal signature was on the form had higher understanding. Of those who signed the form themselves 73 percent understood the term advance directive. Sixty-five percent of individuals whose form was signed by an individual from the facility and only 52 percent of those who did not sign a form demonstrated an understanding of directives.

Patients who understand advance directives are more likely to either have or consider obtaining an advance directive. For example, 34 percent of those who understand already have a directive and another 48 percent would consider obtaining one. Only eight percent would not consider an advance directive and five percent did not know. In contrast, among those lacking understanding of directives only seven percent have a directive and only 18 percent would consider one, while 37 percent would not consider one and 23 percent did not know. Among patients who understand directives, understanding is higher for living wills (63%) than for durable power of attorney for health care (41%).

Hospital Documentation by Patient Characteristics

Documentation and Existence of Directives Varied by Patient Age

The presence of an advance directive was better documented in the medical charts of older patients. Similarly, the older the patient, the more likely they were to have an advance

Age	18-30	31-45	46-60	61-75	> 75
Charts Documented	67.0%	81.0%	87.6%	87.5%	86.7%
Have Directive	8.6%	11.2%	20.9%	20.9%	34.6%
Directive in Chart	81.8%	61.5%	76.0%	76.0%	55.8%

directive. However, the younger age groups were more likely to have a copy of the directive in their chart.

Existence and Documentation of Advance Directives Varied by Patient Payment Type.

Medicare patients had the highest percent of well documented charts, with the exception of a very small number of self-pay⁸ patients. Medicare patients also had more advance directives than any other payment group. In contrast, Medicaid patients had the poorest documentation and fewer advance directives compared with other pay groups. However, HMO and Medicaid patients had the highest percent of directives present in the chart.

	Medi- caid	Medi- care	HMO	Private Insurance	Other
Documented	74%	87.5%	84%	82.4%	80.7%
Have Directive	8.1%	30.8%	23.1%	21.3%	19.2%
Directive Present	75%	53.6%	87.5%	51.7%	53%

Some Patients With Life Threatening Diagnoses Lacked Documentation.

Missing documentation and documentation stating "unknown" were noted in 13 percent of patient charts with diagnoses that could be considered life threatening. These diagnoses included cancer, pneumonia, sepsis and thrombosis. In addition, 41 patients lacking documentation had a diagnosis of pregnancy. These patients represented 39 percent of all pregnancies reviewed.

Hospital Education Efforts

The Great Majority of Hospitals had Provided Staff and Community Education

All but one hospital had provided education to the staff on the topic of advance directives. The hospitals having the largest percentages of charts with documentation provided staff education at regular staff meetings, as opposed to new employee orientation or regular staff inservice training. However, the most prevalent means of educating the staff was through regular inservice training.

Eighty-three percent of the hospitals had provided, or planned, some form of community education. The most common method was having a member of the hospital staff provide a talk or participate in a discussion on the topic in settings such as senior citizens centers, schools, churches and a variety of other locations. Forty percent of the facilities providing education had either mailed or distributed materials to the public on advance directives. Some of the hospitals provided materials at community health fairs or blood drives. Finally, 45 percent of facilities providing education had done so through press articles, either in local newspapers or hospital publications.

Hospitals Reported Similar Approaches for Informing Patients

Ninety-five percent of the hospitals provided written materials on the topic of advance directives to all adult patients. Generally, materials were provided by admissions personnel. In addition, 58 percent discussed the information with patients and 54 percent referred patients to another person if they expressed interest in the topic. Seventy-nine percent of the facilities stated they accommodated special needs of patients, with the largest number saying they made information available in other languages, if needed. Twenty-five percent of the hospitals provided information through closed circuit television, or video tape. Finally, eight percent of the hospitals stated they had information available in large type.

Hospital Problems and Suggestions

Many Hospitals Reported Implementation Problems and Challenges

A variety of individuals responsible for implementing the advance directive provisions were interviewed in each hospital, including selected special staff and legal counsel in some facilities. Seventy-five percent of hospitals stated they had experienced either some kind of difficulty in implementing the Act or they had concerns about the impact of some of its requirements. The most common problem mentioned was the time involved. Hospitals stated it was difficult to address advance directive information during admission, as it adds to the length of the process. Further, if the information was not provided or obtained during admission, additional time was required for follow-up, frequently requiring direct care personnel involvement in the process. This could create difficulties due to constraints on direct care staff time. In addition, adding advance directives to the admission process required additional time to explain the information. One hospital stated they admitted approximately 100 patients a day. Thus, the added time required to provide the information, became a serious issue in terms of additional resource requirements. Finally, one hospital stated that implementing the requirements of the Act had required a great deal of time to develop materials, and change procedures and admission forms.

The second most frequently cited difficulty was patient confusion and apprehension regarding the information. Some hospitals stated the language was difficult to understand or the terms used for directives were not consistent. Others stated patients often thought

the hospital was trying to tell them they were going to die, or that having a directive was an admission the individual was going to die. One hospital stated some patients were concerned that the facility was trying to obtain their money if they should die, since the patient was confusing a directive with a legal will.

Four facilities mentioned that obtaining a copy of the directive from the individuals who already had one was a problem. Often the patients did not know where their directive was located or they were not aware that they should bring a copy to the hospital. Four facilities also mentioned that it was difficult to document whether a patient had a directive and provide the required information if the patient was admitted through an alternative process, such as from a clinic, the emergency room or after hours. Two facilities further stated it was difficult to follow-up and reach these individuals at a later time during their hospital stay.

The expense involved in implementing the Act was cited as a problem by three facilities. Added expenses were incurred due to the need for more staff, the development of additional materials, the changing of forms and the need to provide community education. Three facilities also mentioned problems with the education requirements. Hospitals stated educating their large staffs and the community was difficult, due to the resources and time required, but was important so patients would enter the hospital with a better understanding of directives.

Hospitals Offered Suggestions to Improve Implementation of The Advance Directive Provisions

Emphasis on pre-arrival awareness: Hospital providers were asked if they had any suggestions regarding methods of improving patient understanding on the topic of directives and methods of providing the required information to patients. The responses focused on the need for greater patient awareness and understanding before they arrive at the hospital for care. It was felt this would alleviate patient confusion and apprehension when discussing the topic and determining if the patient had a directive. It would also allow the admission process to flow more smoothly and quickly.

Community education: The most commonly mentioned suggestion for enhancing awareness revolved around continued community education efforts by the hospitals, coupled with efforts of outside agencies, the media and the government. Ten facilities suggested government involvement in patient education. It was suggested that the Health Care Financing Administration make information available to Medicare clients when they initially sign up for services. It was suggested that information should also be made available to Medicaid recipients, perhaps through the Health Department. Another suggestion was a mass mailing on advance directives by the Surgeon General, as has been done on other topics, and that public service announcements on the topic be provided. In addition, facilities suggested the IRS could include information on the topic with their forms, insurance agencies could participate in education on the topic and that the American Association For Retired Persons could provide public education. Finally, wallet

cards similar to Medi-alert cards or bracelets to indicate if an individual has an advance directive were suggested.

Physician education and involvement: Nine facilities mentioned the need to educate physicians and to increase their involvement in discussing advance directives with patients. It was stated that physicians may not have a firm understanding of advance directives, thus continuing education and education of medical students on advance directives should be provided. In addition, it was felt that patients had difficulty comprehending details about advance directives in the hospital setting and physicians should initiate discussions on the topic in the less stressful setting of their office before the need for hospitalization arose.

Uniformity: Finally, seven hospitals expressed the need to make the information provided on advance directives and forms more uniform and more easily understood. It was suggested that simple brochures written at the sixth grade level, with illustrations, be utilized and that the information presented from facility to facility be consistent. Furthermore, it was suggested that the terms utilized to address advance directives be uniform, as the terminology often varied by state and sometimes by facility. A suggestion was made that materials be mailed to individuals who were to be admitted to the hospital prior to their admission so they could familiarize themselves with the topic. Finally, facilities stated that knowledgeable individuals must be available at facilities to explain the information they provide to patients. It was suggested that individuals explaining this information could either be patient advocates, or nursing staff.

NURSING FACILITIES

Sample Characteristics

- 24 Nursing Facilities
- 424 Charts
- 113 Interviews of patients/interested others

Patient Understanding

Patient understanding of advance directives varied by type and size of nursing facility as well as by method of providing information. A greater percentage of for-profit nursing facility patients demonstrated an understanding of advance directives than patients receiving care from non-profit or public facilities. Patient understanding was also

NF Sample	Patient Understanding
64 For-Profit	79.5%
44 Non-Profit	68.7%
5 Public	40.0%

somewhat higher in smaller facilities. For example, 86 percent of individuals in nursing facilities with 100 or fewer beds, and 72 percent of individuals in facilities of 101 to 150 beds demonstrated an understanding of advance directives. Only 44 percent of individuals associated with facilities over 150 beds demonstrated

understanding. Patients in facilities that discussed information on advance directives demonstrated a greater understanding than those only provided with written materials or referred to another person for discussion.

We found some differences in patient understanding based on payment type. HMO (80%) and self-pay (78%) patients were most likely to have an understanding of advance directives. The group with the lowest understanding of directives was Medicaid (63%) followed by Medicare patients (64%).

The form of provider documentation of advance directives also had some effect on patient understanding. Patients whose facility documented advance directive information on a standardized form (77%) versus a note (69%), had a greater understanding of advance directives. Of the individuals with documentation on a form, 88 percent of those whose form was signed by a responsible party understood the term advance directive. Seventy-nine percent of individuals who signed their own form and 67 percent of those who did not sign a form demonstrated an understanding of directives.

While patients who understand advance directives are more likely to either have or consider obtaining a directive, the difference with those who lacked understanding was not great. For example, 43 percent of those who understand already have a directive and another 16 percent would consider obtaining one. Only seven percent would not consider a directive, two percent did not know and six percent did not wish to answer. Among those lacking understanding of advance directives, 34 percent had a directive and 12 percent would consider one, while 15 percent would not consider one, 16 percent were unsure and nine percent did not wish to answer. Among patients who understand advance directives, there was little difference in understanding of living will (89%) versus durable power of attorney for health care (86%).

Nursing Facility Documentation by Patient Characteristics

Documentation and Existence of Directives Varied by Patient Age

The presence of an advance directive was better documented in the medical charts of younger patients. However the older patients were more likely to have an advance directive as well as have a copy of the directive in the chart.

Age	60 or <	61-75	76-90	>90
Charts Documented	82.3%	65.7%	68.5	69.0%
Have Directive	26.4%	39.6%	42.1%	42.8%
Directive in Chart	77.7%	72.7%	78.7%	88.8%

Documentation, Existence and Presence of Directives Varied by Patient Payment Type.

The presence of documentation, having a directive and having a copy of the directive in the chart varied among payment types. Patients with "other" forms of payment had the highest percentage of well-documented charts, with HMO having the poorest. However, self-pay and HMO patients were most likely to have a directive, while "other", Medicaid and self-pay patients were most likely to have a copy of the directive in the chart.

	Medi- caid	Medi- care	HMO	Private Insurance	Self- pay	Other
Documented	75.0%	72.0%	25.0%	71.7%	78.7%	96.6%
Have Directive	25.6%	37.7%	43.7%	33.3%	53.7%	36.6%
Directive Present	83.7%	78.0%	71.4%	69.2%	81.3%	100%

Some Patients with Life Threatening Diagnoses Lacked Documentation.

Missing documentation, documentation stating unable to comprehend, and documentation located in financial records were noted in 32 percent of the patient charts with diagnoses that could be considered life threatening. These patients had diagnoses such as cancer, congestive heart failure, chronic obstructive pulmonary disease, cerebral vascular disease, pneumonia, sepsis and thrombosis. Sixteen of the patients lacking documentation in the chart had documentation in financial records located in administrative offices. Finally, 12 of the patients without documentation had a diagnosis of alzheimer's disease or dementia.

Nursing Facility Education Efforts

The Great Majority of Nursing Facilities Had Provided Staff and Community Education.

All but one nursing facility had provided education to the staff on the topic of advance directives. The facilities with the largest percentages of charts documented had provided staff education at regular inservice training as opposed to new employee orientation or staff meetings. Regular inservice training was also the most prevalent means of providing education on the topic.

Seventy-one percent of the nursing facilities had provided, or planned, community education. The most common method of community education was providing talks at the nursing facilities for the residents and family members. Talks were provided by physicians, lawyers, and social workers. Some talks were provided by facility staff at community senior citizen centers and a seminar was provided by one facility lawyer. Forty-seven percent of the facilities providing community education had either mailed or distributed materials to the public on advance directives and 18 percent had placed articles in the local press or newsletters.

Information was Provided and Discussed with the Great Majority of Patients

Ninety-two percent of the nursing facilities provided written materials to all adults on the topic of advance directives and 96 percent discussed the topic with the patient or family members. Generally, materials were provided by admissions or social service personnel. If individuals expressed interest in the topic they were referred to another person for further discussion in 37 percent of the facilities. Seventy-one percent of the facilities stated they accounted for special needs of the patient with the largest number stating they made information available in other languages if needed. Twenty-nine percent of the facilities stated they had information available in large type and eight percent made information available in an audio visual format.

Nursing Facility Problems and Suggestions

Many Nursing Facilities Reported Implementation Problems and Challenges.

A variety of individuals responsible for implementing the advance directive provisions were interviewed in each nursing facility, including administrators, admissions directors and social service personnel. Seventy-nine percent of facilities stated they had experienced some kind of difficulty in implementing the provisions. The difficulty cited by the majority of the facilities (14) was the condition of the patient. Some facilities said patients were frequently overwhelmed, traumatized or frightened upon admission due to their illness. Four facilities stated that, for these individuals, admissions was a difficult time to discuss advance directives. Further, some family members preferred to discuss the information with the patient themselves. Other facilities stated many patients were too debilitated or were not competent to understand information provided to them. In such cases this created problems, since families were often out-of-State or uninvolved which made obtaining information on advance directives either impossible or lengthy. If an individual did have a directive it was often difficult to obtain a copy from the family member. Additionally, some families did not want to hear the discussion about advance directives due to the difficulty of accepting the patient's condition or feelings of guilt.

The second difficulty mentioned by five nursing facilities pertained to understanding of the terms used. Some facilities reported concerns regarding whether the patients actually understood the terms and the implications of medical decisions that would result from

their decisions. Other facilities were concerned about the vagueness of the terms, the differences in state and federal law and the legal implications of the terms.

Nursing Facilities Offered Suggestions to Improve Implementation of The Advance Directive Provisions

Pre-arrival awareness: Nursing facility providers were asked if they had any suggestions regarding methods of improving patient understanding and providing required information on advance directives to patients. As in the hospitals, the responses focused on the need for greater patient awareness and understanding before they arrive at the nursing facility for care. It was felt that prior knowledge could alleviate some of the difficulties experienced by facilities in obtaining information on patient directives and allow the admission process to flow more smoothly.

Community education: The most commonly mentioned suggestion for enhancing awareness revolved around community education efforts and ensuring consideration and execution of directives if they are desired, before entering a nursing facility. Six facilities stated community education should be offered through a variety of avenues. Some suggestions for providing public education were public service announcements, magazine articles, and talk shows. Further suggestions included education by organizations such as the American Association of Retired Persons, senior citizen centers, high schools and insurance companies. Four facilities suggested the government participate in educational efforts by making information available when a person enrolls in any public assistance program, applies for Social Security, Medicare, or obtains a drivers license. Additionally, mailings from Social Security and availability of government brochures were suggested. Finally, two facilities suggested that a system of documenting advance directives on drivers licenses, social security and Medicare cards could be developed. It was felt that such documentation would educate people to carry copies if they had a directive.

Uniformity: A second group of suggestions pertained to both the materials themselves and methods of providing information at the facility. Four facilities cited the need for uniformity in terms as well as forms used for directives. In addition, it was felt that the forms and information should be very simple to enhance understanding and reduce the feeling of being overwhelmed by the information. Two facilities suggested health care facilities in the community could coordinate their efforts in the provision of material to encourage uniformity of information and understanding.

Enhanced understanding: A final suggestion involved increased patient understanding of directives in the facility. Providing follow-up several days after admission along with the availability of individuals having experience with directives to answer questions were mentioned. In addition greater physician involvement and providing the information at the most appropriate time were suggested. It was felt these suggestions would promote understanding of the information provided during the stressful admission process and encourage more than just paper compliance.

HOME HEALTH AGENCIES

Sample Characteristics:

- 24 Agencies
- 538 Charts
- 115 interviews of patient/interested other

Patient Understanding

Patient Understanding Varied by Home Health Agency Characteristics, Payment Type and Documentation Style.

Patient understanding of advance directives varied by type and size of home health agency (HHA). A greater percent of private home health patients demonstrated an understanding of advance directives than those receiving care from other types of agencies, though the differences were not great. Patient understanding was highest in smaller agencies (77%) followed by the larger agencies (65%). Only 45 percent of patients in mid-size agencies, with average case loads between 75 and 150 patients a month, understood. As in hospitals, there was little difference in home health patient

HHA Sample	Patient Understanding
<u>43</u> For-Profit	70%
<u>57</u> Non-Profit	65%
<u>15</u> Public	60%

understanding of advance directives based on whether information was discussed with the patient, provided in written format or if the patient was referred to another person for discussion.

The majority of patients (82.6%) were Medicare recipients, with 68 percent demonstrating understanding of advance directives. Of the remaining payment types, only Medicaid and private insurance had at least ten individuals interviewed. Of these groups, 60 percent of Medicaid patients and 47 percent of private insurance patients demonstrated an understanding of directives.

The form of provider documentation of advance directives also had some effect on patient understanding. Greater understanding was found among patients whose agencies documented advance directives in a note (79%) versus a standard form (56%). However, the largest number of individuals interviewed had a form in their chart. Of those with a standard form, 73 percent of those with no signature demonstrated understanding compared to 62 percent of those signed by the patient. The lowest level of understanding among patients with a form were those with a staff signature (44%).

Patients who understand advance directives are more likely to have an advance directive. For example, 32 percent of those who understand already have a directive, however, only six percent would consider obtaining one. A large number, 25 percent would not consider an advance directives and five percent did not know. In contrast, among those lacking understanding of advance directives only 10 percent have a directive and only 16 percent would consider a directive, while 29 percent would not consider a directive and 18 percent did not know. Among patients who understand advance directives, understanding is

higher for living wills (86%) than for durable power of attorney for health care (78%), although both are high.

HHA Documentation by Patient Characteristics

Documentation and Existence of Directives Varied by Patient Age

The presence of an advance directive was better documented in the medical charts of older patients. Similarly, the older the patient, the more likely they were to have an advance directive. However, the younger age groups were more likely to have a copy of the directive in their chart.

Age	18-45	46-60	61-75	76-90	>90
Charts Documented	66.6%	78.5%	77.7%	74.4%	66.6%
Have Directive	5.5%	19.0%	21.0%	26.3%	22.2%
Directive in Chart	0.0%	12.5%	17.1%	5.8%	0.0%

Existence and Documentation of Advance Directives Varied by Patient Payment Type.

Once again only Medicare, Medicaid and private insurance payment types had a sufficient number of patients to compare differences in documentation. Of these three payment types, private insurance patients had the highest percentage of documented charts, patients with a directive and patients with a directive present.

	Medi- caid	Medi- care	Private Insurance
Documented	65.0%	75.7%	80.87%
Have Directive	7.6%	23.1%	25.5%
Directive Present	25.0%*	8.8%	12.5%

* represents only one case

Some Patients With Life Threatening Diagnoses Lacked Documentation.

Missing documentation and documentation stating "unable to determine" or "unable to comprehend" were noted in 26 percent of patient charts with diagnoses that could be considered life threatening. The diagnoses of these patients included cancer, chronic heart failure, chronic obstructive pulmonary disease, cerebral vascular accident, and pneumonia. In addition to these patients, three patients lacking documentation had a diagnosis of pregnancy.

HHA Education Efforts

While Only Half of The Home Health Agencies Had Provided Community Education, All Had Provided Staff Education.

All home health agencies had provided education to the staff on the topic of advance directives. The agencies having the largest percentages of charts with documentation

provided education almost equally at regular staff inservice training and new employee orientations, as opposed to staff meetings. However, the most prevalent means of providing education on the topic was through regular staff inservice training.

Community education had been provided, or planned, by 50 percent of the home health agencies. The most common method of community education was mailing or distributing information to members of the community. Additionally, 36 percent of the agencies providing inservice training had a staff member discuss advance directives and 27 percent had placed articles either in local newspapers or agency publications.

Home Health Agencies Reported Similar Approaches for Informing Patients

All of the home health agencies provided written materials on the topic of advance directives to all adult patients. Generally, materials were provided by the nurse or therapist making the first evaluative visit. In addition, 96 percent discussed the information with patients and 54 percent referred patients to another person if they expressed interest in the topic. Seventy-five percent of the facilities stated they accommodated special needs of patients, with the largest number saying they made information available in other languages, if needed. Seventeen percent of the agencies provided information in large type and four percent had a video tape available.

HHA Problems and Suggestions

Many Home Health Agencies Reported Implementation Problems and Challenges.

A variety of individuals responsible for implementing the advance directive provisions were interviewed in each home health agency, including director/administrators, quality assurance personnel, and nurses. Seventy-nine percent of facilities stated they had experienced some kind of difficulty in implementing the Act. The difficulty cited most frequently by agencies (8) was the condition of the patient. Some agencies stated that, frequently, patients had poor cognition at admission or were overwhelmed by the process due to their illness. Six agencies stated that many patients have been "bombarded" with information on directives before entering home care, are tired of hearing the information, and are wondering why they are being given this information. Additionally, several agencies cited the lack of patient knowledge on the subject, the confusion in the terms used for the types of directives and the inability to answer the patients' legal questions as being problematic.

The second group of difficulties was more general in nature. Four facilities cited the extra time and additional burden placed on the individuals performing the already long initial evaluation procedure. Four agencies also mentioned that if an individual had a directive it was difficult to obtain a copy, since they were frequently not kept at home. Furthermore, two facilities mentioned the difficulty in honoring a directive if 911 is called, as paramedics ignore the directive even if it is communicated to them. Finally,

two facilities cited the cost involved in implementing the requirements, particularly in developing forms and educational materials.

Home Health Agencies Offered Suggestions to Improve Implementation of The Advance Directives Requirements

Community education: Home Health providers were asked if they had any suggestions regarding methods of improving patient understanding on the topic of directives and methods of providing the required information to patients. The responses focused on the need to reach patients more effectively with information on the topic before medical care is required. Nine agencies stated that more public education should be provided by the media and a variety of groups. National advocacy groups, community groups such as the Kiwanis, churches, funeral homes and public schools were cited as possible groups to provide education. Three agencies cited the need for doctors to be more involved in the education of their patients on advance directives. Additionally, four agencies stated that the government should be more involved in the public education efforts, providing brochures for utilization by small home health groups, and working with national home health groups to communicate information on directives. Furthermore, it was felt that Medicare and Social Security should engage in providing information to recipients. Six agencies also suggested that materials and terminology should be both simplified and made more uniform to promote greater understanding by patients and reduce confusion on the topic.

Sharing information: A second suggestion provided by the home health agencies pertained to coordinating efforts to reduce replication of paperwork pertaining to advance directives. Five facilities suggested hospitals and home health agencies could share patient records and forward advance directive materials if one service followed the other. In addition, it was suggested that patients who were readmitted to care several times throughout the year could have documents on file so that materials and services would not have to be replicated. This would not only make the evaluating nurse/therapists job more manageable, but would also reduce the number of times an individual would have to be presented with the materials. It was felt this would reduce the antagonism some patients feel about the repetition of advance directive information.

ENDNOTES

1. The Patient Self-Determination Act was enacted as section 4206 and 4751 of the Omnibus Reconciliation Act of 1990, P.L. 101-508. It was originally introduced as S. 1766 by Senators Danforth and Moynihan, and H.R. 5067 by Congressman Sander Levin.
2. Levin, Sander, D. MI, Remarks in the House of Representatives on H.R. 5067; Patient Self-Determination, Thursday, Jun 28, 1990, CR page E-2190.
3. McCloskey, Elizabeth Leibold, "The Spirit of the PSDA", *Practicing the PSDA*, Hasting Center, Sept-Oct 1991, pg S14.
4. Kamer, R.S., et al, "Effect of New York States Do Not Resuscitate Legislation On In Hospital Cardiopulmonary Resuscitation Practice", *American Journal of Medicine*, 1990, vol 88, pgs. 108-111.
5. Tarnowski, K.J., et al, "Readability of Pediatric Biomedical Research Informed Consent Forms", *Pediatrics*, 1990, vol 85, pgs. 58-62.
6. Berman H, Rose L., *Choosing the Right Health Care Plan*, Mount Vernon N.Y. 1, Consumers Union, 1990, 3.
7. La Puma, John, et al, "Advance Directives on Admission, Clinical Implications and Analysis of the Patient Self-Determination Act of 1990", *JAMA*, July 1991, Vol 266, no.3, pgs. 402-405.
8. Self-pay patients had the highest percent of hospital charts with documentation present indicating whether or not the person had a directive. However, the number of self-pay patients included in the hospital sample was only 12, representing only two percent of the sample. In addition, none of the self-pay patients had an advance directive. For these reasons self-pay results were omitted from the table.