

Patients' Attitudes Toward Advance Directives

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Abstract:

Purpose: To explore hospitalized patients' attitudes toward advance directives, their reasons for completing or not completing advance directive forms, and demographic differences between patients who did and did not complete advance directive forms.

Design and Method: The convenience sample comprised 30 hospitalized patients in North Carolina. Participants were interviewed using an adapted advance directive attitude survey (ADAS), and were asked five general questions about advance directives. Validity and reliability were established on the adapted tool.

Findings: The overwhelming majority of participants had received information on advance directives and they were moderately positive about them. The majority who had completed advance directives were Caucasian, female, over age 65, had less than a high school education, and perceived their health as poor. Most believed that an advance directive would ensure they received the treatment they desired at the end of life.

Conclusions: Patients' attitudes alone did not determine who will and will not complete advance directives. Most participants who completed advance directives had specific reasons for doing so. Nurses have responsibility for discussing advance directives with patients, families, and physicians to ensure adequate education about the completion of advance directives.

Key words: advance directives, patient self-determination act

Article:

Decisions about life-sustaining treatment are frequent during end-of-life care, and they become difficult when patients' wishes have been neither documented nor discussed with either primary health care providers or family members. Advance directives such as the living will and durable power of attorney for health care (DPAHC) allow patients to make decisions in advance regarding medical treatment at the end of life, or to designate someone to make those decisions for them. Recording their wishes increases the likelihood that preferences will be communicated to family members and physicians, and therefore will be honored when people have lost the ability to express themselves (Parkman, 1996).

The Patient Self-Determination Act (PSDA), enacted in the United States in 1990 and implemented in 1991, requires hospitals, skilled nursing facilities, home health agencies, hospices, and health maintenance organizations (HMOs) receiving Medicare and Medicaid

funding to provide information about advance directives to all patients and to inform them of their right to complete an advance directive (Omnibus Budget Reconciliation Act, 1990).

Since the implementation of the PSDA, advance directives have received widespread attention, and health professionals and patient advocates have demonstrated overwhelming support for them. Hospital administrators have instituted aggressive educational programs to inform patients about advance directives, and all 50 states have enacted legislation supporting advance directives (Sabatino, 1996). Yet despite these efforts to increase education of patients about advance directives, the number of people initiating advance directives remains low, between 5% and 25% (Cugliari, Miller, & Sobal, 1995; Perry, Nicholas, Molzahn, & Dossetor, 1995; Reilly et al., 1995).

Several researchers have explored reasons advance directives are not initiated. Early studies showed that lack of knowledge (High, 1993a) and inaccessibility to advance directive documents (Morrison, Olson, Mertz, & Meier, 1995) were the primary reasons advance directives were not initiated. Efforts to improve both education (High, 1993a; Reilly et al., 1995) and accessibility (Morrison et al., 1995) have failed to increase the number of advance directives initiated. Reasons patients perceive advance directives as either positive or negative, and the effect those perceptions have on the decision to initiate advance directives have been explored in only a few studies. Murphy and colleagues (1996) found that participants with low socioeconomic status, no personal experience with illness or withholding care, and no private health insurance were more likely to have negative attitudes toward advance directives. Further, people with negative attitudes toward advance decisions were 90% less likely to possess an advance directive document than were respondents with positive attitudes.

Only two studies included factors that affect patients' decisions to execute advance directives. In a qualitative study of hospitalized patients, Rein and colleagues (1996) found that the decision to initiate advance directives was based on desire to maintain control over treatment decisions, relationships with family, acuity versus chronicity of illness, and perceptions of health care professionals' roles in treatment decisions. In a survey to determine why people aged 65-93 prepared advance directives, High (1993b) found that 41 % of those surveyed indicated a desire not to burden their family as the primary reason, and 33 % indicated a desire to be kept off artificial life support.

Understanding why people choose to act or not to act on their right to make decisions in advance for care at the end of their lives requires understanding their knowledge, attitudes, and beliefs, and the effects of these factors on each other and on behavior. This study therefore was done to explore hospitalized patients' attitudes toward advance directives, their reasons for completing or not completing advance directives, and demographic differences associated with completion of advance directive documents.

Caralis, Davis, Wright, and Marcial (1993) found that African Americans were more likely than were Hispanics or non-Hispanic Caucasians to believe they would be less cared for if they had an advance directive. Hispanics were more likely to defer decisions about end-of-life care to their family members, but non-Hispanic Caucasians were more likely to allow physicians to make those decisions. Murphy and colleagues (1996) and Perry and colleagues (1995) found no

significant relationship between age and completion of advance directive documents, but Hammes and Rooney (1998), Jacobson and colleagues (1996), Reilly and colleagues (1995), and Silverman and colleagues (1995) found that older patients were more likely than were younger patients to have advance directives. Jacobson (1996) found that women were more likely to execute advance directives, though Reilly and colleagues and Murphy and colleagues found no correlation between gender and the presence of an advance directive. Jacobson (1996) and Schonwetter, Walker, and Robinson (1995) found that patients with either a chronic or terminal illness were more likely than were others to have advance directives, but Reilly found no association between either diagnosis or severity of illness and the presence of advance directives.

METHODS

Setting

Data were collected over a 3-week period in the oncology and medical-telemetry units of a teaching hospital in central North Carolina. The 36-bed oncology unit has primarily patients with cancer and sickle cell disease, but it also receives overflow patients, some of whom are HIV positive or have AIDS. The 37-bed medical-telemetry unit has patients with acute and chronic medical conditions such as cardiac, gastrointestinal, respiratory, and cerebrovascular disorders. Approximately 50% of the patients on the unit have congestive heart failure.

Sample

A sample of convenience was obtained from the two inpatient units. To be included in the study, patients had to: (a) speak English, (b) be 18 years of age or older, (c) be oriented to person and place, and (d) have been approached by an RN regarding advance directives, as documented in the patient chart.

A list of patients admitted to the units who were at least 18 years of age was obtained from the charge nurse or nurse manager. Registered nurses assigned to patients on the list were asked whether the patients met the inclusion criteria. Patients who met all four criteria were asked to participate in the study until 30 consented to do so. Appropriate institutional review board approvals were obtained to ensure the protection of human subjects.

Instrument

The instrument used to collect data was an adapted version of Nolan and Bruder's (1997) advance directive attitude survey (ADAS). Demographic data were also obtained and participants were asked five general questions about their perceptions of personal health, whether they had ever received information on advance directives, whether they had ever completed an advance directive, and whether they had ever had a discussion with either their primary physician or family members about end-of-life care.

The ADAS (Nolan & Bruder, 1997) was developed in 1996 to measure patients' attitudes toward advance directives on two medical units in a tertiary care teaching hospital. The tool is a 16-item, 4-point Likert scale designed to determine the extent to which advance directives are viewed as positive or negative; respondents answer from 1 (strongly disagree) to 4 (strongly agree). Higher scores indicate more favorable attitudes toward advance directives. The original tool included items about: (a) opportunity for treatment choices, (b) effect of advance directives on the family, (c) effect of an advance directive on treatment, and (d) perception of illness. Content validity was established using a panel of experts. Cronbach's alpha for the instrument was .74.

With the author's permission, the original tool was revised to include eight additional items reflecting patients' perceptions of: (a) whether advance directives affect the amount and quality of care received at the end of life, (b) whether decisions regarding end-of-life care can be changed once an advance directive is initiated, and (c) who patients want to make decisions about their end-of-life care. Content validity for the adapted tool was determined by having a panel of five experts, including the author of the original, review the tool before use and answer questions about the appropriateness of content. To establish temporal stability, a sample of 25 professional and nonprofessional people from the community completed the survey approximately 2 weeks apart. Using Pearson's correlation coefficient, test-retest reliability was established at .8. On the first administration of the test to this group Cronbach's alpha was .75. Cronbach's alpha was .86 for the study sample.

Each participant was given a copy of the ADAS and was asked to follow along as the researcher read each question. Then participants verbally indicated which response best matched how they felt about each item. Upon completion of the interview, each person was asked to sign the completed survey acknowledging that the information was correct and given voluntarily. Participants were also asked to sign a statement granting permission to obtain the following information from the chart: (a) diagnosis, (b) presence of an advance directive, and (c) type of insurance.

FINDINGS

Sample Characteristics

Sixty-two patients who met the study criteria were asked to participate in the study. Twenty-nine patients declined; 9 cited fatigue or discomfort, 3 did not want to discuss advance directives, and 17 were not interested. Of the latter 17 patients, one said she did not have to worry about advance directives because she had private health insurance, one indicated that advance directives were unnecessary if you had someone you trusted to make those decisions, and one said advance directives were unnecessary because "Jesus will make all of those decisions." The 29 patients who refused to participate were comparable in gender and race to the participant group. Three patients who consented to participate were unable to complete the study for various reasons.

Table 1. Comparison of Scores ($n=30$) on Advance Directive Attitude Survey (ADAS) by Race, Sex, Age, and Level of Education

Patient characteristics	Mean	Median	SD
Race			
Caucasian ($n=19$)	66.9	67.0	5.7
African American ($n=10$)	67.2	64.5	7.7
Hispanic ($n=1$)	63.0	63.0	—
Sex			
Male ($n=11$)	65.2	65.0	4.1
Female ($n=19$)	67.9	67.0	7.2
Age			
20 to 34 years ($n=3$)	64.7	64.0	4.0
35 to 49 years ($n=9$)	67.9	67.0	7.1
50 to 64 years ($n=5$)	65.2	65.0	4.4
65 years and older ($n=13$)	67.4	67.0	7.1
Education			
Less than high school ($n=10$)	63.0	64.5	3.9
High school ($n=13$)	70.0	69.0	6.8
Bachelors degree or more ($n=7$)	66.7	66.0	5.4

Participants with the highest mean scores were African American, female, aged 35 to 49 years, and with a high school education (see **Table 1**). Of the 30 patients who participated in the study, 11 were men and 19 were women. They ranged in age from 24 to 85 years, with a mean age of 57 years ($SD=17.2$). Nineteen were Caucasian, 10 were African American, and 1 was Hispanic. Ten had completed grade school or junior high, 13 completed high school, 4 completed college, and 3 had master's degrees or beyond. Seven participants described their health as poor, 9 described it as fair, 12 good, and 2 very good. Six participants indicated this was their first hospitalization in the last 2 years, 18 had been hospitalized between two and five times, and 6 had been hospitalized more than five times in the last 2 years. Diagnosis on admission included cancer for 12 people, respiratory disorders for 5, sickle cell disease for 4, cardiac disorder for 3, vascular disorders for 2, and 1 each had gastrointestinal, musculoskeletal, neurological, and dermatological disorders.

Twenty-three people (77%) had received information on advance directives, and 7 (23%) said they had received no information. Several participants, however, indicated that they had been offered information but refused it. Of the 23 patients who had received information on advance directives, most (73%) had received information on more than one occasion. Seventy-four percent of patients had received information while in the hospital, and the remaining 26% had received information from a lawyer, church official, home care provider, or physician in a clinic. Thirteen (43 %) of the 30 subjects had completed advance directives, but 17 (57%) had not (see **Table 2**). Types of advance directives completed included health care power of attorney (8%), living will (31%), and both health care power of attorney and living will (61%). Four of the 13 patients who had completed advance directives had the directive documents on their charts.

Table 2. Advance Directive Attitude Survey (ADAS) Scores of Patients' Attitudes Toward Advance Directives and End-of-Life Decisions

Completed advance directive	<i>n</i>	Mean	Median	<i>SD</i>
Yes	13	69.5	68.0	5.0
No	17	64.9	63.0	6.6

Patients' Attitudes Toward Advance Directives. To explore patients' attitudes toward advance directives, mean and median scores on the ADAS were examined. The possible range of scores on the ADAS is 22 to 88; higher scores indicate more positive attitudes toward advance directives. Total scores in this study ranged from 57 to 83, with a mean of 66.9, median of 66, and standard deviation of 6.3, indicating a moderately positive attitude toward advance directives.

Not surprisingly, the mean score for those who had completed advance directives was higher than for those who had not done so. All participants who indicated they had completed advance directives scored 65 or above on the ADAS.

The two participants with the highest scores on the ADAS each reported more than 10 hospitalizations in a 2-year period, and described personal experiences related to the need for

advance directives. One person had been on a ventilator previously and voiced strong opposition to being placed on a ventilator in the future. The other person had experienced sibling turmoil about making decisions about end-of-life treatment for both her mother and father, and indicated that she would not put her children in that position. The people with the two lowest scores on the ADAS had had fewer than three hospitalizations in the last 2 years, and both disagreed with the statement that an advance directive would make sure that their family knew what treatment they desired and they would receive the treatment they desired. One person said she would not complete an advance directive, and the other expressed discomfort about making end-of-life decisions.

Participants who completed advance directives were more likely than were those who did not to have had discussions with their physicians and their families regarding their wishes for treatment at the end of life. Of the 54% who indicated they did not have a discussion with their physicians regarding end of life treatment, only two said their physicians were aware that they had completed advance directives.

All 30 participants believed they would be given choices about the care they received at the end of life. Twenty-nine people said that if they were unable to make decisions at the end of life, family members would be given choices about the treatment they would receive. Twenty-eight people thought that their physicians would include their concerns in decisions about treatment at the end of life and 28 said that having an advance directive would ensure their family knew their treatment wishes. Twenty-five participants said their families would want them to have an advance directive, and having one would prevent family members from disagreeing over their treatment at the end of life. Nineteen said that having an advance directive would prevent family guilt over treatment decisions, and 23 said that having an advance directive would prevent costly medical expenses for their family. Twenty-seven subjects indicated that an advance directive would ensure that they received the care they desired at the end of life, and 28 thought making an advance directive should be done when one was healthy.

Nevertheless, only 13 participants had completed advance directives. Reasons cited for doing so included: (a) desire not to be placed on life support (54%), (b) desire to name someone to make decisions in event of incapacitation (54%), desire to make decisions easier for spouse or family (31%), failing health (15%), and (e) advancing age (8%).

The 17 patients who did not complete advance directives gave these reasons: (a) keep putting it off (41%), (b) not necessary at this point in my life (24%), (c) uncomfortable making decisions about life support (18%), (d) never heard of advance directives before (18%), (e) form was too long (12%), (f) trust husband to make those decisions (6%), and (g) advance directives are unnecessary (6%). Two participants who indicated that an advance directive was not necessary at this point in their life also described their health as poor or fair.

Six participants said they were not sick enough to have advance directives, and seven said they still had a lot of time to decide on them. Yet 3 of the 6 participants who indicated they were not sick enough to have advance directives described their health as poor or fair, and two of those who indicated they still had a lot of time to decide on advance directives described their health as poor or fair.

All participants indicated that they wanted to make decisions about their care as long as they were able to. Nineteen participants said they wanted both their families and their physicians to make decisions if they were unable to do so, 10 wanted family members to make those decisions, and only 1 wanted his physician to make that decision.

DISCUSSION

The majority of people in this study believed that they had choices about medical treatment at the end of life and that advance directives would ensure that they received the treatment they desired. Seventy percent reported that they had received information on advance directives, and many had received information on more than one occasion and from multiple sources. Only two people had never heard of advance directives. Although this sample was small and the findings must be viewed with caution, the study nevertheless indicates that most hospitalized patients were exposed to information about advance directives, but many did not have complete advance directives.

The completion rate for advance directives in this study (43%) was higher than in many previous studies (Cugliari et al., 1995; Nolan & Bruder, 1997; Perry et al., 1995; Reilly et al., 1995; Silverman et al., 1995). One reason may be that the sample included a significant number of people who were over age 64, had a chronic or terminal illness, had been hospitalized multiple times in a relatively short period, and described their health as fair or poor.

The mean total score on the ADAS indicates that participants were moderately positive about advance directives. This finding is consistent with Nolan and Bruder's (1997) findings. As would be expected the mean score on the ADAS was higher for those who completed an advance directive than for those who did not. This result is consistent with Murphy and colleagues' (1996) finding that the more positive people are toward advance directives, the more likely they are to complete them.

In this study the people most likely to initiate advance directives were Caucasian, female, and over age 65, who perceived their health as poor, and had less than high school education. The number of women who completed an advance directive was three times the number of men who did so. The fact that no one in the 20 to 30 year age group completed an advance directive, while 62% of people over age 65 had completed them indicates, not surprisingly, that advancing age contributes to the decision to complete advance directives. Further, 86% of participants who described their health as poor completed advance directives; thus, perception of health appears to be an important factor in deciding whether to complete an advance directive.

Only six people who had completed advance directives had had a discussion of end-of-life treatment with their physicians and only 31 % who had advance directives had them on their charts. These findings illustrate the problem of inaccessibility of advance directives and subsequent failure of advance directives to affect care. The top two reasons for completing an advance directive—a desire to maintain control over treatment decisions and a desire to be kept off artificial life support—were also among the top reasons identified by Rein and colleagues (1996) and High (1993b).

The reasons given by participants for not completing advance directives were consistent with those found in the literature. Perceived barriers to the initiation of advance directives include the following: (a) lack of understanding of advance directives (Palker & Nettles-Carlson, 1995; Schonwetter et al., 1995), (b) insufficient information on advance directives (High, 1993b; Palker & Nettles-Carlson, 1995; Silverman et al., 1995), (c) lack of access to advance directive forms (Cugliari et al., 1995), (d) lack of understanding about how to complete the form (High, 1993b), (e) lack of prior discussion with physician, and (f) family disagreement on decisions about medical treatment (Schonwetter et al., 1995).

Nurses working in the study hospital ask all patients whether they have completed advance directives and whether they want information on advance directives. Information and the appropriate documents are provided to interested patients. Patients who indicate that they have completed advance directives are encouraged to have a family member provide a copy for the chart. Follow-up and patient education are lacking, however, as shown by the relatively few patients in this study who completed advance directives and the number of patients with advance directives who failed to: (a) provide the hospital a copy of the completed document, (b) discuss advance directives with their physicians, and (c) discuss their desires for end-of-life treatment with their physicians.

As patient advocates, nurses can take that education a step further. Patients who complete advance directives need to know that unless their wishes have been communicated with their physicians and families, and the document is present on the chart, their wishes will not be carried out. Many patients assume that completion of an advance directive is all that is needed to receive the care they desire at the end of life, but that is not the case. Nurses can help by letting physicians know when patients have advance directives. Nurses also need to explain what advance directives are when asking patients if they have an advance directive. They can explore alternative ways to educate patients about advance directives (e.g., videotape), and follow up with patients who have requested information to see if they have additional questions or need assistance completing an advance directive.

People who recognize the need for advance directives, are aware of the benefits, and believe that advance directives affect care positively at the end of life may be more apt to complete advance directive documents. Long-term studies are needed to determine the extent to which advance directives affect end-of-life care, and to identify factors that prohibit advance directives from positively affecting care.

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