Role of Written Advance Directives in Decision Making

Insights from Qualitative and Quantitative Data

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OBJECTIVE: To understand the role of written advance directives (ADs) in medical decision making through examination of qualitative and quantitative data sources. We specifically wanted to address whether physicians unilaterally disregard advance directives.

DESIGN: Block randomized controlled trial to improve decision making and outcomes of seriously ill patients.

SETTING: Five academic medical centers.

PATIENTS: Fourteen hospitalized, seriously ill adults were randomized to receive an intervention of patient-specific information on prognoses and specially trained nurse to facilitate decision making. To be included in this analysis, patients reported having an AD and also met one of these criteria of severity: were comatose, had objective estimate of prognosis for surviving 2 months of 40% or less, or died during this hospital admission.

MEASUREMENTS AND MAIN RESULTS: Quantitative data sources consisted of medical record review and interviews with the patient (when possible), surrogate, and responsible physician about prognosis, symptoms, preferences, and decision making. Qualitative data consisted of narratives by the nurse responsible for counseling and facilitating decision making. Each element of the quantitative database was reviewed, and a timeline of communication and decision making was constructed. Qualitative data were analyzed using grounded theory and narrative summary analysis. We compared and contrasted qualitative and quantitative data to better understand the role of ADs in decision making. In each case, the patient had a period of diminished capacity in which ADs should have been invoked. Advance directives played an important role in decision making of 5 of 14 cases, but even in those cases, life-sustaining treatment was stopped only when the patient was "absolutely, hopelessly ill." In two of these cases, the family member wrongly reported that the patient had an AD, and in the remaining seven cases, ADs had a limited role. The limited role could not be traced to a single explanation.

Rather, a complex interaction of several factors was identified: patients were not considered hopelessly ill, so the directive was never seen as applicable and a transition in the goals of care did not occur; family members or the designated surrogate were not available, were ineffectual, or were overwhelmed; or the content of the AD was vague, or not applicable to the clinical situation, and the intent in completing the AD was never clarified. A physician did not unilaterally disregard a patient's preference in any of the cases. Two factors that enhanced the role of the AD were an available surrogate who was able to advocate for the patient and open communication between the physician and the surrogate in which the patient's prognosis was reconsidered.

CONCLUSIONS: Our findings indicate that physicians are not unilaterally disregarding patients' ADs. Despite the patients' serious illnesses, family members and physicians did not see them as "absolutely, hopelessly ill." Hence, ADs were not considered applicable to the majority of these cases. Cases in which ADs had an impact evidenced open negotiation with a surrogate that yielded a transition in the goals of care.

KEY WORDS: right to die; advance directives; living will; decision making; terminal-care methods.

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For the past three decades, physicians, ethicists, and jurists have struggled with the issue of decision making for those who are seriously ill and have diminished cognitive capacity. Advance directives (ADs), written documents that provide instructions (often called living wills) or name a surrogate decision maker (often called durable power of attorney [DPOA]), are one legal method by which patients may state preferences in advance of a period of incompetence.

The impact of written ADs on decision making remains uncertain. Two studies suggest that merely enhancing the awareness and documentation of ADs could lead to substantial monetary savings.¹⁻³ However, one randomized trial and a prospective, observational study have questioned the role of ADs in decision making for the dying and seriously ill.^{4,5} The limitations of these studies have been noted. For example, only a small number of patients were incompetent prior to death in the randomized trial conducted by Schneiderman and colleagues.⁴ In the study of hospitalized, seriously ill adults, the impact of ADs was studied only on resuscitation decision making, and daily assessment of patients' competency could not be undertaken in a study of nearly 10,000 patients.⁵

Acknowledging the limitations described above, this multimethod research effort examines the role of ADs in

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medical decisions among patients with a sustained period of diminished mental capacity. Our aim was to understand what were the barriers and aids to facilitating ADs' role in decision making for hospitalized, seriously ill adults. We used both qualitative data (in this case, nurse-written narratives about the course of decision making) and quantitative data (abstracted data from the medical record and interviews with patients, surrogate decision makers, and physicians) to gain a more complete understanding of the complex social interactions around decision making about life-sustaining treatment for hospitalized, seriously ill adults.

METHODS

Study Population

The methods used by SUPPORT have been reported previously.^{6,7} Between January 1992 and January 1994, SUPPORT enrolled patients meeting entry criteria at five academic hospitals. All participants consented to the intervention, and this study was reviewed by each institutional review board. Entry criteria required specified, advanced stages of at least one of the following diseases: nontraumatic coma, acute respiratory failure, multiple organ system failure with sepsis or malignancy, chronic obstructive pulmonary disease, congestive heart failure, cirrhosis, colon cancer, or non-small-cell lung cancer.⁶ These criteria were chosen to identify a cohort with an expected aggregate mortality rate of approximately 50% at 6 months. Patients were excluded if they died or were discharged within 48 hours of admission; were admitted with a scheduled discharge within 72 hours; had AIDS, multiple trauma, or were pregnant; were under age 18; or were known not to speak English.

Data Collection Methods

This analysis utilizes both quantitative and qualitative data sources. Quantitative data were gathered from concurrent and retrospective medical record reviews and from structured interviews with patients, their surrogates, and the patients' physicians.⁸⁻¹⁰

In interviews conducted in the first and second week of hospitalization, patients and surrogates were asked whether or not they had talked to their physician about prognosis, resuscitation, and their preferred approach to care, the patient's self-perceived prognosis, quality of life, and the patient's ability to function. This interview was repeated if the patient was alive at months 2 and 6 after hospitalization. If the patient died within the 6 months of follow-up, the family member was interviewed about the circumstances of the patient's death.

The physician responsible for decision making was interviewed during the first and second week after study admission to determine whether or not the patient had a written AD, if that AD helped or hindered decision mak-

ing, the physician's perception of patient preferences for resuscitation, approach to care, and quality of life, and whether or not the physician discussed the patient's prognosis and preferences with the patient or surrogate. Response rates for the patient, surrogate, and physician interviews were greater than 80%, with the exception of the second-week patient interview (71%) and second-week surrogate interview (78%).

The qualitative data are narratives written by an intervention nurse shortly after the patient's death or discharge from the hospital. The nurses wrote narratives on every tenth intervention patient and on other cases, called "critical incidents," which provided them with special insight into decision making or the intervention. Because the nurses knew which patients they would write about, they kept actual quotations from patients, families, and health care providers on contact sheets (which the nurses used to document all types of interaction with patients). Nurses were told that the main purpose of these narratives was to gain better understanding of how medical decisions unfolded and how the intervention affected patient care. Nurses were instructed that narratives must address the following categories: the patient's clinical situation; the circumstances of the family and any financial concerns; intervention course; outcomes of intervention; and course of pain. For the selection of the nonrandom or critical incident cases, the nurses were instructed to choose the case that they found the most meaningful, typical, or challenging.

Sampling

Cases were selected based on report of the patients having a written AD and meeting at least one of the following criteria: comatose as defined by a Glasgow coma score of 9 or less; a 2-month prognosis for survival of 40% or less; or death during the enrollment hospitalization. We further required that at least one interview with either the surrogate or patient and one interview with the physician must have been conducted.

This yielded a total of 58 potential cases, including 11 narratives that were written on every tenth patient and 47 critical incidents. We analyzed the 11 narratives first and sampled the remaining 47 critical incident cases until we were no longer identifying new themes or gaining new insights regarding the role of ADs, yielding 14 cases. One of the authors (MS) reviewed all the remaining 44 to see if these critical incident narratives provided different insights or refuted our findings. They did not, and the findings of the 14 cases are presented.

Approach to Quantitative Data

One of the authors (JMT) reviewed all available information for a given case and summarized the patient's clinical course by writing a several-page memorandum and constructing a timeline of clinical course and decision

making. Available data sources included medical record review and closed-ended interviews with patients, surrogates, and physicians, survival predictions, and decision making about life-sustaining treatment documented in the medical record. From review of these data, summaries were formulated and written about the case. Next, this reviewer read the narrative. She prepared a list of areas in which the narrative increased knowledge about the case and a list of discordant events and interpretations.

Approach to Qualitative Data

The narratives on every tenth patient ranged in word count from 37 words (about a patient who died shortly after study enrollment, with whom the nurse did not have contact) to 1,904 words. The median count of words was 943. The critical incidents were generally more narrowly focused and proved less suitable for analyses.

The narrative data were entered into Ethnograph. One author (JMT) carried out a content analysis of each narrative in conjunction with her analysis of the quantitative data. Another author (MS) conducted a grounded theory analysis.¹¹ She read all 58 narratives in the sample and conducted open coding to generate hypotheses about ADs and applied axial and selective coding to all narrative material for the cases in which both qualitative and quantitative data sources were reviewed and triangulated.

Finally, one author (MS) conducted a narrative summary analysis.¹²⁻¹⁴ Using this technique, she extricated and retold the story of each participant for whom enough data existed in the narrative to construct a story. In the 14 cases of our final sample, we were able to tell the patient's and surrogate's stories and often to add the stories of other family members and health care providers.

Qualitative analysis raises issues about reliability and validity. We have followed the recommendations of Inui and Frankel.¹⁵ First, we kept a complete analysis notebook, available for review by outside reviewers. Second, we kept an open diary that documents the development of our themes. Third, we asked about other interpretations in the data and refuted them in the data. Fourth, we subjected our conclusions to three formal reviews. A group of qualitative researchers who were not associated with the SUPPORT project reviewed our case book and critically assessed our conclusions. We presented our conclusions in a 90-minute seminar of epidemiologists and biostatisticians at Dartmouth Medical School. Finally, we conducted a telephone conference call with the nurses who wrote many of the narratives in the sample. All three audiences found no major problems and provided helpful comments that were incorporated.

RESULTS

Fourteen cases underwent triangulation of both the qualitative and quantitative data sources. The average patient age was 65 years, with the majority of the sample

being male (57%) and white (86%). Fourteen percent of the case subjects were African Americans. More than one half (57%) died on the enrollment admission. In comparison with the SUPPORT population,⁷ subjects included in this analysis differed in that they were more likely to have died on the enrollment admission (57% vs 26%, $p < .001$). This finding was consistent with our case selection criteria.

Advance directives played an important role in decision making in 5 of the 14 cases (Table 1). This role varied from naming an atypical surrogate (the divorced ex-wife of a patient who developed persistent vegetative state after an automobile crash) to facilitating a transition in the goals of care and the withdrawal of life-sustaining treatment. Such transitions occurred after the use of life-sustaining treatment and frank discussions with a family member.

Often, these transitions happened after soul-searching by the family member about the right time to withdraw treatment. A nurse wrote about one wife's struggle to make the right decision: "At that time, the patient's wife expressed concern that the patient not be kept alive if there was no hope of recovery, that those were his wishes, and she wanted to honor them . . . her question was how would she know when to stop?"

In another 5 of the 14 cases, we believed that the AD could have had more importance in decision making (Table 2). In three of these five cases, however, the failure to discuss the AD or clarify the intent of the AD resulted in clinical care that seemed inconsistent with patient preferences. In 4 of the 14 cases, the role of the AD was limited or there was no formal written AD (Table 3).

Narrative Themes

Our aim was to generate explanations for how ADs either facilitated or failed to facilitate decision making. After analysis of these 14 narratives, we identified three main themes that helped illuminate why the role of ADs was limited. We did not see evidence in any of the cases that a physician unilaterally decided to ignore or disregard an AD. Rather, we saw a complex interaction of the following three themes: patients were not seen as "absolutely, hopelessly ill," and thus, it was never considered the time to invoke the AD; the contents of ADs were vague and difficult to apply to current clinical situations; and family members or the surrogate designated in a DPOA were not available, were ineffectual, or were overwhelmed with their own concerns and did not effectively advocate for the patient.

Advance Directives Are Applicable Only When Patients Are Hopelessly Ill

In each of these cases, the intent of the ADs was to withhold or withdraw life-sustaining treatment under certain circumstances. None of these patients had an AD with the intent to request maximal or aggressive treat-

Table 1. Cases in Which the Advance Directive Aided in Decision Making*

Description of the Case	Type of Directive/ Surrogate Report of AD Impact	Worst Glasgow Coma Score	Length of Stay	
			Days in Hospital	Days in ICU
Male, age 65, with non-Hodgkin's lymphoma admitted post transfusion reaction. He developed respiratory failure, and when an infectious etiology was ruled out, wife and physician made decision to stop life-sustaining treatment. Despite being described as distraught, the wife honored her husband's AD.	Living will, DPOA/ "Helped a little"	0	10	6
Male, age 75, with acute respiratory failure from viral pneumonia received aggressive life-sustaining treatment that was stopped on the 10th study day. The patient wanted aggressive treatment maintained unless there was no hope, and care was consistent with his preference.	Living will/ "Helped a great deal"	0	15	15
Male, age 50, in an automobile accident, remained comatose and was transferred for evaluation of persistent vegetative state. He had DPOA that named his ex-wife as his surrogate. She made decisions on DNR and ICU care, but she did not decide on nutrition and hydration. She felt limited to make this decision by his sister who was very religious and thought only "God could decide."	DPOA/ "Helped a great deal"	6	21	2
Male, age 70, with 4 ADL impairments hospitalized for experimental protocol for metastatic colon cancer. His preference was to receive aggressive medical care unless there was no hope. That preference was honored with a DNR order and forgoing vasopressors on his 8th study day, just 2 days prior to death. His wife profoundly regretted the decision to undertake the research protocol and that her husband died in the hospital and not with family.	Living will/ "Helped somewhat"	10	10	0
Female, age 85, admitted with seizure from metastatic endometrial cancer to the brain. Her son, a physician, orchestrated transfer to hospice and she died at home.	Living will, DPOA/ "Caused minor problems"	5	30	2

*Age and identifying characteristics have been changed to protect confidentiality.

ment. For health care providers and family members, the most difficult question, as posed by one patient's wife, was "knowing when to stop." In all cases in which life-sustaining treatment was withheld or withdrawn, this decision was made after a trial of life-sustaining treatment and at a time when the patient was seen as "absolutely, hopelessly ill" or "actively dying." Until patients crossed this threshold, ADs were not seen as applicable.

For example, a 70-year-old patient with metastatic colon cancer and impairment in four activities of daily living (ADLs) was hospitalized for an experimental chemotherapy protocol. This patient wanted life-sustaining treatment withdrawn only when there was no hope for his survival. He received aggressive treatment until 2 days before death, when vasopressors were withdrawn. Care was consistent with the patient's preferences, and the patient's wishes were followed. This pattern of aggressive treatment, however, caused significant regret to his wife: "Her husband's poor outcome was very hard for her to bear, making her reexamine the decision to undertake the therapy and regret that during the last few days he was unable to enjoy his family."

In the above case, the patient's preferences were paramount in guiding terminal care. In most cases, however,

the intent of the patient's AD was less clear, and life-sustaining treatment was stopped only when medical treatment was perceived to be futile. This is best illustrated by the case of a 75-year-old woman admitted for induction chemotherapy for lymphoma. The patient developed septic shock as a consequence of the chemotherapy. She died after an 18-day stay in the intensive care unit (ICU). The housestaff physician requested a meeting of the ICU staff and the oncology attending physician to discuss the goals of care. At the time of this meeting, the patient had a predicted likelihood of 6-month survival less than 1%. The SUPPORT nurse's narrative noted the oncologist as saying that, "He did not give chemotherapy to patients and then have them come out like this, and that this was the expected course of treatment, and that her counts would be coming up soon."

The patient was asked about withdrawal of the mechanical ventilator at her bedside: "He [the attending physician] asked if she wanted the breathing tube out, and she said that she did. The [attending physician] said, 'Well let me restate that if the breathing tube comes out, then you will die.' There was pregnant pause, and then she, after a while, shook her head not, but feebly. The attending quoted and documented that she had a 25% of recovery.

Table 2. Cases in Which the Advance Directive Could Have Aided Medical Decisions

Description of the Case	Type of Directive/ Surrogate Report of AD Impact	Worst Glasgow Coma Score	Length of Stay	
			Days in Hospital	Days in ICU
Male, age 70, with preexisting colon and lung cancer admitted to the hospital for new-onset ataxia. He completed a living will and voices that he is going to die and does not want surgery. However, this was not discussed with surgeon. He became obtunded, and emergency surgery was undertaken. Based on discussion with the primary care physician and wife, care was potentially at odds with his preferences. However, the patient was not seen as dying, and the AD was not seen as applying. The wife was distraught and unable to make decisions.	Living will/ "Helped a great deal"	8	31	7, with 15 d in a step- down unit
Female, age 80, from nursing home who previously stated that she wanted "no heroics." The patient developed a gastrointestinal bleed. Her colon was perforated at the time of colonoscopy. This resulted in an 81-day stay on a ventilator. Her preference of "no heroics" was not clarified. Based on an interview with the nephew (the proxy in the DPOA), he stated in open-ended question that the AD was ignored.	Living will, DPOA/ "Wishes were not followed"	0	86	45
Male, age 70, with end-stage renal disease with a specific AD that was overridden by his wife so that his daughter could come to terms with her father dying. A decision was made for hospice care 4 days prior to death.	DPOA/ "Helped a great deal"	3	20	0
Female, age 75, admitted for induction chemotherapy for lymphoma. Her husband desperately wanted her to live. The intent of her AD was not clarified, and questions were asked of the patient in a biased manner. On the day of death, a decision was made to withdraw the mechanical ventilator and forgo resuscitation.	Living will, DPOA/ No information from proxy or MD	11	23	18
Female, age 65, who developed a cerebellar bleed after thromboplastin therapy for acute myocardial infarct. Daughter, the named proxy in the DPOA, was unable to make decisions, and the patient was discharged to nursing home with recurrent hospitalizations.	Living will, DPOA/ "There was nothing about DNR in AD"	0	41	14

When he said that to the patient with the husband near the bed, the husband held out four fingers and said, "Twenty-five percent, honey, that is just one of these four fingers. Grab it. Grab it." She reached up her hand and grabbed one of the fingers. [The husband] said, "There, you've got it; there, you've got it."

In this circumstance, the housestaff physician and the intervention nurse believed that the patient was requesting withdrawal of the mechanical ventilator. After this conversation, the patient continued to receive aggressive treatment for another 2 weeks. On the day of her death, the ventilator, feeding tube, and vasopressors were withdrawn. The patient was never seen as dying by the attending physician or her husband until the last day of her life, and the opportunity was never taken to discuss what was her intent in completing the living will while she was still competent.

Problems with Surrogacy

Even when the patient had a living will, decisions were made after discussion with a surrogate, either the person named in a DPOA or someone informally selected among family members. In several cases, we found that surrogates were unavailable, ineffectual, or too over-

whelmed with their own concerns to advocate effectively for the patient.

For example, in one case an elderly woman named her nephew as her proxy in a DPOA. The nephew was in his eighth decade of life and lived in a small community some 2 hours' drive from the hospital. Because of his inability to drive to the hospital, the nephew was unable to advocate for the patient's best interests. Physicians were often unavailable via telephone, and from the nephew's perspective, they did not pay attention to his aunt's ADs. In an open-ended question in his interview, the nephew responded with the following comment: "Her wishes were not followed at the hospital. I told them there was a living will and durable power of attorney."

In another case, a 70-year-old patient with a previous history of colon and lung cancer developed new-onset ataxia. Workup revealed a new cerebellar mass. The patient completed a living will with a social worker and expressed the belief that he was going to die to his young grandson. He never had the opportunity to discuss the living will with his physician. The patient acutely decompensated and underwent a shunting procedure.

The wife was aware of his AD and his wishes: "[The patient's wife] was more concerned about the possibility, as we have just discussed, that he had told her grandson

Table 3. Cases in Which There Was No Advance Directive or Advance Directive Had a Limited Impact on Decision Making

Description of the Case	Type of Directive/ Surrogate Report of AD Impact	Worst Glasgow Coma Score	Length of Stay	
			Days in Hospital	Days in ICU
Male, age 80, admitted to the ICU with acute myocardial infarct and aspiration pneumonia requiring mechanical ventilation. Patient indicated a preference for a DNR. His daughter (who was the DPOA for the estate) attempted to override his preference and make the patient full code. Intervention nurse noted that there was no DPOA and that the competent patient's preferences are to be followed. On the 5th study day the patient's ventilator was withheld and patient died.	Living will/ Daughter who tried to override her father's preferences noted that AD "helped a great deal"	13	12	5
Female, age 75, with cerebrovascular accident that resulted in functional dependency and aphasia. Patient lived in nursing home and was admitted multiple times with aspiration pneumonia.* The daughter, who was the surrogate named in the DPOA, made a decision to forgo resuscitation. However, the issue of recurrent hospitalizations and mechanical ventilation was not addressed until late in the clinical course.	DPOA/ "Helped a great deal"	0	11	2
Female, age 65, with metastatic lung cancer with brain metastases admitted from home hospice with a seizure. She was admitted to the ICU. The attending physician recognized the son as the decision maker and decisions were made for DNR and order to forgo mechanical ventilation. Study staff spoke with her husband, who voiced preferences for treatment to be tried if thought to help.	Living will/ MD states AD "helped a great deal"; no surrogate interview	3	10	0

*This is the 2nd of 5 admissions prior to death.

that he didn't think he would come be coming home from the hospital. [Patient's wife] went on to explain that he had insisted on doing a living will before surgery and he wouldn't want to be kept on life support."

The surgeon believed that the patient had a more favorable short-term prognosis. However, the surgeon was perceived by the nursing staff as being less than frank with the wife about the patient's prognosis: "... the [physician's] lack of frankness about the long-term prognosis that the [floor nurse] perceived to be poor in view of the patient's multiple illnesses, including cancer, the poor postop recovery."

The wife (described as hysterical and at the patient's bedside asking him to wake up) was unable to make the decision that was most likely the patient's intent in completing the AD: "Mrs. [X], told me that she didn't know 'if I could make the decision that he wanted me to . . . I just hope that he can wake up enough to say what he wants.'" In this case, Mrs. X was not the declared proxy in a DPOA. The patient completed only a living will. However, all decisions were discussed with her, and the intent of the living will was never considered.

Facilitating the Role of Advance Directives in Decision Making

In contrast, the key to facilitating the role of either a living will or DPOA in decision making was a surrogate who was available and able to advocate effectively for the patient. A second important and closely linked theme was the existence of open and shared communication between health care providers and the surrogate about the goals of

care. Quite often, the key to a successful impact of the AD was reconsideration of the patient's prognosis and further discussion about the intent of that AD. We found that having an able surrogate and having shared communication went hand in hand with ADs' achieving their goal of respecting patient wishes.

These two themes are illustrated by the story of a 65-year-old man with non-Hodgkin's lymphoma who was admitted with a fever after a presumed transfusion reaction. The patient became progressively dyspneic, which required the use of a mechanical ventilator. The wife was described by the intervention nurse as emotional, the husband having always assumed the role of protector and provider for his wife.

On the initial meeting with the intervention nurse, the patient was quite short of breath, but the intervention nurse noted that the wife did not see the patient as seriously ill: "Mrs. S. indicated that both she and her husband had a living will, but that she didn't think he was that sick. She noted that it seemed odd to have the conversation as her husband had, only a night or so before, awoken during the night to tell her that he thought he might be nearing the end and to reiterate his desire not to have his dying prolonged with 'machines.'"

The patient's clinical status deteriorated, and the oncology fellow discussed again the patient's prognosis, and the physician and wife negotiated the goals of care. The wife, described as "tearful and emotional," effectively advocated for her husband: "The fellow reviewed the prognosis for the lymphoma, which he described as poor, given the length of time the patient had been ill and his poor re-

sponse to multiple courses of chemotherapy and radiation. He explained that it seemed likely that Mr. S had pneumonia, but that it was difficult to tell for sure as the symptoms of lymphoma were also reflected in fever and altered cell counts . . . Dr. Y suggested . . . [that] a bronchoscopy was an option that might present the health care team with information about what was occurring in Mr. S's lungs. He also explained that Mr. S was having to work very hard to breathe and that intubation and ventilation might be necessary to support him during the testing. Mrs. S tearfully told Dr. Y that they had a living will and that her husband wouldn't want to be on machines. She felt she could agree to intubation and ventilation only if the goal was to treat the pneumonia and if she could be promised that the machines would be taken off, should they only be used to 'prolong his life.' . . ."

Two days later the wife, family, and health care providers reconsidered the patient's prognosis based on the results of the bronchoscopy and bone marrow biopsy: "The results from the bronchoscopy were unremarkable and did not help clarify the situation much (although it did increase the suspicion that the process was more malignant than infectious) . . . a bone marrow was performed, with heart-breaking results. Once again, we had a family meeting, this time with the ICU attending physician, the ICU fellow, Mrs. S, daughter, the ICU nurse and respiratory therapist, and myself [the intervention nurse]. Another intense and tearful meeting was held, with decisions to change the goal of therapy to palliation, to attempt to wean from the vent, to change code status to DNR [do not resuscitate], and to make sure the patient was comfortable."

DISCUSSION

Advance directives represented an important conceptual step forward in end-of-life care in the early 1970s. At that time, the fundamental debate at the patient's bedside dealt with the morality of withholding and withdrawing life-sustaining treatment, which is now a routine practice. Nevertheless, this multimethod research effort, our previous research, and research of others attest to the need to improve and enhance the formulation and implementation of ADs for the seriously ill.^{4,5,16-18}

In this study, we further refined a methodology of combining qualitative and quantitative data sources to gain insight into an exceedingly complex behavior—the role of written ADs in end-of-life decision making. Each data source provided important complementary information about the role of written ADs in medical decision making. For example, when the husband told his wife that she had a 1-in-4 chance of living (" . . . the husband held out four fingers and said, 'Twenty-five percent, honey, that is just one of these four fingers. Grab it. Grab it.'"), it is quite sobering to know that an objective estimate of prognosis based on the SUPPORT statistical model indicated less than 1-in-100 chance of surviving

180 days. This research effort also gave us the opportunity to respond to an important criticism of our earlier work—that the impact of ADs ought to be examined among those with a period of diminished mental capacity.

On the basis of this research, we believe that the effectiveness of ADs could have been improved and enhanced substantially. These narratives attest to the need to recast ADs from the formal, legal process of signing a document to a more dynamic process of communication and negotiation about the goals of care, which we and others have called "advance care planning."¹⁹⁻²¹ To that end, we have identified some important barriers and aids to facilitating the role of ADs in decision making and creating a new vision for advance care planning.

Communicate Early and Reconsider the Patient's Prognosis and Goals of Care

As patients die, the patient, family, and health care provider often negotiate a transition in the goals of care, generally from a goal of extending life at nearly all costs to a goal of patient comfort, even at the result of an earlier death. Living wills often state that if one is terminally ill, one does not want burdensome treatment and the goals of care should focus on comfort. Despite this prominence of ADs, our study reveals that in practice it can be difficult to know when one is no longer just very sick, but actively dying.

For the most part, we found that transitions in goals of care were considered only when the patient was hopelessly ill. Given this finding, it is not surprising that our previous research has shown that those with ADs did not differ in timing of DNR orders or patterns of resource utilization from those without ADs.^{5,16} From this narrow perspective, ADs do achieve their goals—when treatment is futile, it is withdrawn or withheld. Mostly, however, the same treatment decisions occur without a written AD. As illustrated by the narrative cases, this pattern of decision making often causes regret for family members who wish that a loved one had died differently.

For advance care planning to be successful, a shared dialogue and negotiation between the health care provider and the surrogate is necessary. This dialogue must start early in the illness and continue through each stage of the illness. The story of Mrs. S and Dr. Y best illustrates a negotiation in which the wife and physician considered the prognosis and the patient's preference at each major decision point.

Choose an Effective and Available Surrogate

Even when a living will was available, health care providers invariably discussed decisions to limit life-sustaining treatment with a surrogate decision maker. A surrogate decision maker is often faced with the task of both advocating for the patient and accepting that a loved one is dying. This is extremely difficult, but not an impossible task.

Our results attest to the need for health care providers to counsel patients about how to best complete ADs, including naming a proxy who is physically and emotionally able to serve in that role. Similarly, the health care team can help the surrogates by defining their role in decision making. A surrogate's role is not to decide whether or not to "pull the plug," but to answer the important question, "What would my loved one decide if she could speak to us?" For example, in the case of the 70-year-old man with cerebellar mass, his wife was unable to make decisions and was often found crying hysterically at the bedside, asking the patient to wake up. This surrogate's perception of her role was that she had to make the decision. It is possible that she would have been better able to advocate for her husband if she understood that her role was providing information about his wishes.

This multimethod research and our previous quantitative research^{5,16,17} illustrate important opportunities to reengineer ADs to meet the needs of patients and their families. Key to reengineering written ADs is that we reconceptualize them as advance care planning, a process of communication and negotiation. At the heart of this endeavor is decision making about the transition in the goals of medical care that respects the patient's wishes and values. These discussions are the cornerstone of patient-centered medical care and should start well before the patient is recognized as "actively dying." A second important aspect of advance care planning is selecting effective and available surrogate decision makers. Health care providers have a pivotal role in advance care planning—they must consider and reconsider the patient's prognosis and ensure that medical treatment is achieving the goals valued by that patient.

The reader should bear in mind some important limitations of this study. We examined the role of ADs in five academic medical centers across the country and in patients with at least one of nine high-mortality diagnoses. Different results may be obtained at different hospitals or with different diseases. In addition, the narrative data were based on 14 written stories of nurses who were part of the SUPPORT intervention. They had a unique perspective as participant-observers, and the narratives reflect their biases. These nurses did not tape-record conversations. Thus, any direct quotations are based on their memory and may inaccurately reflect what was actually stated. Similarly, the 14 cases included 3 critical incidents identified because of their salience. Although these 3 cases may not have been representative of the underlying population, analysis after excluding for those cases yielded the same narrative themes and conclusions.

Despite these limitations, our research attests to the opportunities to improve the current use of ADs and the value of collecting narrative data as part of an evaluation of a complex social phenomenon. The combination of these complementary data sources yields insight into the current use of ADs and ways to improve and enhance medical care such that it is both patient and family centered.

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REFERENCES

1. Weeks WB, Kofoed LL, Wallace AE, Welch HG. Advance directives and the cost of terminal hospitalization. *Arch Intern Med.* 1994; 154:2077-83.
2. Chambers CV, Diamond JJ, Perkel RL, Lasch LA. Relationship of advance directives to hospital charges in a Medicare population. *Arch Intern Med.* 1994;154:541-7.
3. Thomasma DC. Functional status care categories and national health policy. *J Am Geriatr Soc.* 1993;41:437-43.
4. Schneiderman LJ, Kronick R, Kaplan RM, et al. Effects of offering advance directives on medical treatments and costs. *Ann Intern Med.* 1992;117:599-606.
5. Teno J, Lynn J, Wenger N, et al. Advance directives in end of life decision making: lessons from the Patient Self Determination Act and the SUPPORT Project. *J Am Geriatr Soc.* 1997;45:500-7.
6. Murphy DJ, Knaus WA, Lynn J. Study population in SUPPORT: patients (as defined by disease categories and mortality projections), surrogates, and physicians. *J Clin Epidemiol.* 1990;43:11-28S.
7. The SUPPORT Investigators. A controlled trial to improve outcomes for seriously ill hospitalized patients: the study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT). *JAMA.* 1995;274:1591-8.
8. Knaus WA, Wagner DP, Draper EA, et al. The APACHE III prognostic system: risk prediction of hospital mortality for critically ill hospitalized adults. *Chest.* 1991;100:1619-36.
9. Teasdale G, Jennett B. Assessment of coma and impaired consciousness: a practical scale. *Lancet.* 1974;2:81-3.
10. Cullen DJ, Civetta JM, Briggs BA, Ferrara LC. Therapeutic intervention scoring system: a method for quantitative comparison of patient care. *Crit Care Med.* 1974;2:57-60.
11. Glaser BG, Strauss AL. *The Discovery of Grounded Theory: Strategies for Qualitative Research.* New York, NY: Aldine DeGruyther; 1967.
12. Gilligan C. *In a Different Voice: Psychological Theory and Women's Development.* Cambridge, Mass: Harvard University Press; 1982.
13. Mischer E. *Research Interviewing: Content and Narrative.* Cambridge, Mass: Harvard University Press; 1986.
14. Maxwell JA. *Qualitative Research Design: An Interactive Approach.* London, UK: Oxford University Press; 1996.
15. Inui TS, Frankel RM. Evaluating the quality of qualitative research: a proposal pro tem. *J Gen Intern Med.* 1991;6:485-6.
16. Teno JM, Lynn J, Connors AF, et al. The illusion of end-of-life resource savings with advance directives. *J Am Geriatr Soc.* 1997; 45:513-8.
17. Teno JM, Licks S, Lynn J, et al. Do advance directives provide instructions which direct care? *J Am Geriatr Soc.* 1997;45:508-12.
18. Morrison RS, Olson E, Mertz KR, et al. The inaccessibility of advance directives on transfer from ambulatory to acute care settings. *JAMA.* 1995;274(6):478-82.
19. Teno JM, Lynn J. Putting advance care planning into action. *J Clin Ethics.* Fall 1996:100-8.
20. Teno JM, Nelson HL, Lynn J. Advance care planning: priorities for ethical and empirical research. *Hastings Cent Rep.* 1994;24(suppl): S32-6.
21. Emanuel L. Structure advance planning: is it finally time for physician action and reimbursement? *JAMA.* 1995;274(6):501-3.