

Elderly Outpatients' Understanding of a Physician-Initiated Advance Directive Discussion

Kathleen A. Moore, MA; Joseph H. Danks, PhD; Peter H. Ditto, PhD;
Jennifer A. Druley, MS; Aileen Townsend, PhD; William D. Smucker, MD

Objective: To examine elderly outpatients' understanding of advance directives (ADs), cardiopulmonary resuscitation (CPR), and artificial nutrition and hydration (ANH) with and without the benefit of a physician-initiated discussion.

Design: Randomized controlled trial.

Setting: University-affiliated, community-based, urban family practice residency training program.

Patients: One hundred patients aged 65 and older, consecutively sampled and randomly assigned to one of two discussion groups.

Interventions: Physicians' discussions based on a prepared script consisting of AD issues or health promotion issues.

Main Outcome Measures: Test of comprehension of AD, CPR, and ANH information, using open-ended

and yes-or-no questions.

Results: Patients in the AD and health promotion discussion groups showed good basic understanding. Younger and better-educated patients had a better working knowledge of AD-related information. Understanding of ADs was higher when the physician spent more time talking about AD-related issues after the discussion was completed.

Conclusions: Many elderly outpatients have a good basic understanding of ADs, CPR, and ANH, even without explicit explanations from physicians. However, younger, better-educated patients and those who had longer unstructured discussions had greater AD-related knowledge. These factors need to be considered when framing discussions with patients about ADs and life-sustaining treatments.

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PHYSICIAN-PATIENT misunderstanding is an important problem in many types of health care interactions.¹⁻⁶ Accurate understanding of medical information is especially important when patients are asked to participate in medical decisions, as when individuals express their preferences for life-sustaining therapies in advance directives (ADs) for medical care. With the passage of the Patient Self-Determination Act,⁷ elderly patients are increasingly being encouraged to make decisions about their life-support preferences before being unable to make responsible decisions. The purposes of this study were (1) to examine the extent of elderly outpatients' comprehension of AD-related issues, (2) to determine whether comprehension is improved by discussing these issues with a physician, and (3) to identify whether specific characteristics of the

patient, physician, physician-patient relationship and of physician-patient discussion predict differences in comprehension.

Many proponents of ADs recommend routine physician-initiated discussions with healthy elderly outpatients,^{1,8-11} and several studies have examined patients' abilities to comprehend AD-related information.¹²⁻¹⁹ Elderly persons have demonstrated accurate understanding of state laws concerning "right to natural death,"¹² but they often confused wills with living wills and instructions for life-sustaining treatments with burial instructions.¹³ In one study, only 59% of elderly adults could provide at least some description

From the Department of Psychology, Kent (Ohio) State University (Mss Moore and Druley and Drs Danks, Ditto, and Townsend), and the Family Practice Center of Akron (Ohio), Summa Health System (Dr Smucker).

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PATIENTS AND METHODS

STUDY PATIENTS

Patients of the Family Practice Center of Akron, Ohio, aged 65 and older, who had completed at least one prior visit with their physician were eligible for the study. For 6 months, patients fitting this description who were scheduled for or who had just completed a physician's visit had their medical records screened for exclusion criteria. Exclusion criteria were spousal participation in the study and charted diagnosis of dementia, depression, schizophrenia, severe communication disorder, or terminal illness. One hundred three patients who met the inclusion criteria agreed to participate in a study about health care decisions. Potential patients were not told that the study was about ADs, living wills, or life-sustaining treatments.

SAMPLE-SIZE CALCULATION

Multiple regression analyses planned for the data from the AD discussion required the greatest number of patients. Assuming a maximum of eight predictor variables per regression equation, setting α at .05 and statistical power at 0.80, 70 patients provided adequate power to detect medium-to small-size effects ($R^2 = .20$).²⁰ Because multiple regression analyses were planned for the AD discussion data only, the HP discussion data did not require an equal number of patients. Post hoc power analyses were computed²¹ assuming the obtained difference in means (and obtained SDs) as the best estimate of the "true" difference under a directional hypothesis, ie, the AD mean is greater than the HP mean. These powers are reported in the "Results" section. Numbers that were randomly assigned to all elderly patients' charts were used to assign 87 patients to the AD discussion group and 16 patients to the HP discussion group.

PREDISCUSSION INTERVIEW

Two graduate student assistants in psychology (K.A.M. and J.A.D.) interviewed each patient in person. The interview began with a screening test for dementia (Short Portable Mental Status Questionnaire [score of >5])²² and for depression (Center for Epidemiological Studies–Depression

Scale [score of >15]).²³ The interview continued with the Positive and Negative Affect Schedule,²⁴ the Multidimensional Health Locus of Control Scale,²⁵ the Medical Outcomes Study Short Form,²⁶ and questions measuring attitudes toward the use of life-sustaining treatments. Additional data collected during the interview and from medical records included gender; age; race; religion; years of education; marital status; living arrangements; whether the patient had executed a will, a living will, or other advance care document; number of visits to current physician; months with physician; number of hospitalizations in the previous 5 years; number of chronic illnesses; and number of long-term medications.

PHYSICIAN VISIT

After patients completed the prediscussion interview and their scheduled physician visit, their physicians presented the AD or HP discussion. All physicians, five faculty and 15 residents, received training in the conduct of study discussions to improve standardization.

AD Discussion

Physicians' discussions were based on a prepared script. The script consisted of five sentences discussing the purpose of ADs, six sentences describing CPR, and four sentences describing ANH. Physicians were instructed to read the sentences verbatim, but to expand on the written script as needed and to answer any questions raised by patients. The script had a Flesch-Kincaid score of 65, corresponding to a seventh-grade reading level.²⁷ Physicians then read two scenarios excerpted from the medical directive document of Emanuel and Emanuel²⁸: (1) coma with a low probability of recovery and (2) an advanced stage of a progressive mental illness. Patients stated their preferences for receiving CPR and ANH in each scenario on a five-point scale, from 1 (definitely do not want) to 5 (definitely want).

HP Discussion

Physicians discussed patient preferences about age-appropriate HP issues excerpted from the US Preventive Services Task Force²⁹ (eg, safety, exercise, diet, immunization).

of cardiopulmonary resuscitation (CPR) before hearing a standard definition.¹⁴ Comprehension of CPR increased following an educational intervention in one study¹⁵ but not in another.¹⁶ In still another study,¹⁷ outpatients and the general public answered 92% of seven simple, factual questions about AD-related issues correctly. However, that study did not control for prior knowledge and did not examine factors such as age or education level that might predict knowledge. A group of elderly patients in a Veterans Affairs hospital who viewed a videotape about ADs increased their understanding of the term "living will," but a group who saw a videotape about preventive health care did not.¹⁸

These studies tested knowledge about a limited range of topics, failed to control for prior knowledge,

or yielded inconsistent results. In the present study, physicians initiated a discussion about the purposes of ADs, CPR, and artificial hydration and nutrition (ANH), or a discussion of health promotion (HP) issues.¹⁹ Inclusion of the HP discussion provided a comparison of knowledge of AD-related issues with and without the benefit of a physician's explanation. After discussions with their physicians, patients in the AD and HP discussion groups were given a test that included items about ADs, CPR, and ANH. Finally, we examined the performance of patients who participated in AD discussions to identify characteristics of the patient, physician, physician-patient relationship, and physician-patient discussion (coded from videotapes of the discussions) that might be associated with higher levels of AD-related comprehension.

Videotape Coding

Portions of the visits containing the physician-patient AD discussions were videotaped and coded.³⁰ To assess how accurately the physicians followed the script, the videotapes were first coded for the number of sentences the physicians omitted from the script. Then, to evaluate which aspects of the physician-patient AD discussions predicted increased comprehension, the total duration was segmented into five portions: (1) physician-patient interaction before the AD discussion; (2) prepared script defining ADs, CPR, and ANH; (3) prepared script describing scenarios to elicit patients' life-support preferences; (4) physician-patient interaction after the AD discussion; and (5) discussions of something other than AD-related issues. The durations (in seconds) of each segment were recorded. Advance directive discussions of 10 patients were not recorded because the videotape technician was absent from work. Videotapes of three additional AD discussions were of such poor quality that coding was not possible. Consequently, videotapes from 72 patients were available for analysis.

AD COMPREHENSION TEST

Immediately following the physician visit and discussion, patients in both groups were tested on their comprehension of the information contained in the prepared script discussing the ADs. Patients were asked nine open-ended questions (three about ADs, three about CPR, and three about ANH) for which responses were recorded verbatim. Following each open-ended question, patients were asked related questions in a yes-no format. These consisted of eight questions about ADs, 16 questions about CPR, and 12 questions about ANH. These questions were evenly split between questions for which the correct response was yes and those for which the correct response was no (**Table 1**).

Correct and incorrect answers to the open-ended questions were coded by three raters according to the information presented to the patients. Interrater reliability was high (Spearman-Brown $r=.89$). Disagreements between the three raters were resolved through discussion. The number of yes-or-no questions patients answered correctly ($n=36$) was scored. Subscores for

AD, CPR, and ANH were calculated by the same method for open-ended and yes-or-no questions.

ANALYSIS

Cronbach α coefficients were greater than .6 for all pre-discussion scales and subscales, with the exception of the life-support attitude items, indicating that the scales were internally consistent. The life-support attitude items were analyzed individually.

To examine preexisting differences between patients in the AD and HP discussion groups, χ^2 analyses were conducted on all demographic and prediscussion variables, and Student's t tests for independent samples were conducted on all continuous variables.

To examine differences between patients in the AD and HP discussion groups on AD comprehension scores, mixed-design analyses of variance were conducted in which one factor compared AD and HP discussion groups and the other compared AD, CPR, and ANH comprehension subscores. Analyses of covariance were also conducted on the AD comprehension scores to control for those demographic and prediscussion variables found to be significantly different between the AD and HP discussion groups.

To examine predictors of AD comprehension, ordinary least-squares multiple regression analyses were conducted on data from the 72 patients for whom videotapes were available. The criterion variables were the patients' overall comprehension scores for the open-ended and yes-or-no formats. Owing to the large number of predictor variables, the regression analyses were performed in two stages.^{19,31} For the initial set of analyses, variables were grouped into six categories: demographics (eg, age), psychological health (eg, depression), physical health (eg, physical function), patient-physician relationship (eg, months with physician), patient views regarding AD issues (eg, attitudes toward life-sustaining treatments), and duration of physician-patient discussion behaviors (eg, preliminary AD-relevant discussion). The significant predictors from each category (based on an inclusion criteria of $P<.15$) were then entered into a final regression equation to determine their relative predictive power.

Differences for all reported analyses were considered significant at $P<.05$.

RESULTS

DESCRIPTION OF THE SAMPLE

No patients were excluded for possible dementia, but two patients were excluded for possible depression (one from each group). One additional patient (from the AD group) was excluded owing to an inability to understand the interview questions. The mean age of the remaining sample ($N=100$) was 72.1 years (range, 65 to 89 years). The sample was 68% female, 48% married, 86% white, and 78% Protestant. The mean years of education was 11.9 (range, 4 to 18 years). Most study participants had a well-established relationship with their physician (evidenced by mean number of months with physician [29.6 months; range, 1 to 192

months] and mean number of visits to their physician [13.1 visits; range, 1 to 73 visits]). Although most patients had recorded a will (71%), few had executed a living will (12%), durable power of attorney (6%), or any other sort of advance care document (3%).

Three significant differences from among 31 demographic and prediscussion variables were found between patients assigned to the AD and HP discussion groups. Patients in the AD discussion group had more visits to their physician, higher levels of depressive symptoms on the Center for Epidemiological Studies-Depression Scale, and more strongly believed that their physician understood their life support wishes compared with patients in the HP discussion group. All analyses of covariances yielded results identical to those found in the corresponding analyses of variances.

Table 1. Patient Comprehension Questionnaire

(a) Open-ended and (b) Yes-or-No Questions	% Correct to Yes-or-No Questions
1. (a) What is an advance medical directive (often called a living will)?	
(b) Does an advance medical directive:	
Indicate a person's wishes about medical treatments?*	96
Indicate the physician's opinions about medical treatments?	65
2. (a) When is the information a patient provides in the advance medical directive used?	
(b) Is the information a patient provides in the advance medical directive used when the patient:	
Enters the hospital for routine surgery?	58
Comes for a routine check-up?	82
Is unable to communicate?*	96
Is unable to make decisions?*	99
3. (a) Why is the advance medical directive important?	
(b) Is the advance medical directive important because:	
It serves as a guide for family, friends, and physicians?*	98
It helps with planning preventive health care measures?	41
4. (a) When is cardiopulmonary resuscitation (CPR) used?	
(b) Do physicians use CPR when:	
A patient has a stroke?	59
A patient stops breathing?*	97
A patient's heart stops beating?*	98
A patient has dizziness?	96
5. (a) When physicians give CPR, what exactly do they do?	
(b) Does CPR involve:	
Giving the patient medications through an IV?	54
Pressing on the patient's chest?*	98
Bandaging the patient's chest?	80
Giving the patient artificial breathing?*	93
Taking x-rays of the patient's chest?	65
Giving the patient an electric shock?*	92
Measuring brain waves?	60
Inserting a heart catheter?	59
6. (a) What is artificial breathing?	
(b) Does artificial breathing involve:	
Providing oxygen through a face mask?	25
Insertion of a tube into a windpipe?*	87
Connecting the patient to a breathing machine?*	98
Asking the patient to breathe rapidly?	85
7. (a) What is artificial feeding and fluids?	
(b) Is artificial feeding and fluids:	
A kind of antibiotic?	57
A form of nourishment?*	97
8. (a) When do patients need to receive artificial feeding and fluids?	
(b) Do patients need to receive artificial feeding and fluids when:	
They are unable to eat or swallow enough food to stay alive?*	95
They have a pain in their stomach?	92
9. (a) How are artificial feeding and fluids given to a patient?	
(b) Are artificial feeding and fluids given to patients:	
As a pill?	86
Through a tube?*	97
(b) Can artificial feeding and fluids be given to a patients through a tube that goes:	
Into a vein?*	80
Into the liver?	95
Into the lung?	87
Through the skin to the stomach?*	85
Through a catheter to the bladder?	76
From the nose to the stomach?*	88

*Indicates the correct response is yes.

Table 2. Mean ($\pm$ SD) Number of Correct Responses to Comprehension Questions*

	Open-ended Questions			Yes-or-No Questions		
	No. of Questions	AD	HP	No. of Questions	AD	HP
Overall comprehension	9	8.2 (2.8)	7.5 (2.9)	36	29.1 (3.3)	29.8 (3.2)
AD comprehension	3	2.7 (2.7)	2.2 (1.4)	8	6.3 (1.1)	6.4 (1.3)
CPR comprehension	3	3.0 (1.4)	2.9 (1.5)	16	12.4 (1.7)	12.7 (1.7)
ANH comprehension	3	2.6 (.92)	2.4 (.96)	12	10.3 (1.6)	10.6 (1.2)

*AD indicates advance directive; HP, health promotion; CPR, cardiopulmonary resuscitation; and ANH, artificial nutrition and hydration.

DESCRIPTION OF THE AD DISCUSSION

Physicians followed the script closely. Of 15 prepared sentences, they omitted a mean ($\pm$ SD) of only 0.14 ± 0.48 sentences (range, 0 to 3). The average total duration for the entire AD discussion was 8.1 minutes (484 seconds). The average duration for each of the five discussion categories were as follows: preliminary AD-relevant discussion, 28.8 seconds; physician presentation of AD information, 196.4 seconds; physician description of life-support scenarios, 132.9 seconds; subsequent AD-relevant discussion, 118.5 seconds; and non-AD-related discussion, 7.0 seconds. A comparison of the five durations showed that most of the discussion time was devoted to the presentation of AD information and the life-support scenarios and to subsequent AD-relevant discussion.

COMPARISON OF AD AND HP DISCUSSIONS ON THE AD COMPREHENSION TEST

Table 2 shows the mean number of correct responses to open-ended questions for overall comprehension, and for each of the three subtopics for both AD and HP groups. The post hoc power for the AD and HP comparison was 0.24. Patients produced about eight correct responses for overall comprehension on average, consisting of two to three correct responses for each subtopic. An analysis of variance (ANOVA) revealed no significant differences in performance level between the two groups on overall comprehension or on any subtopic. Patients in both groups produced an average of a little over one incorrect response (AD=1.01; HP=1.44), but this difference was not significant, and none of the subtopics was significantly different.

Table 2 also shows the mean number and percentage of correct responses to yes-or-no questions for overall comprehension and for each of the three subtopics for both AD and HP groups. The post hoc power of the AD and HP comparison was greater than 0.78. For overall comprehension and for each subtopic, patients in the two discussion groups answered approximately 80% of the questions correctly. An ANOVA revealed no significant differences in performance level between the two discussion groups. In addition, there were no significant differences among the subtopics.

Table 1 shows the percentage of correct responses for each of the yes-or-no questions. There were several

frequently missed items in both the AD and HP discussion groups. For example, only 54% of the patients comprehended and remembered that "When doctors give CPR, they give the patients medications through an IV." There was no consistent pattern of frequently missed items and information topics, although there was a slight tendency for the missed items to be questions for which the correct answer was no, possibly suggesting a response bias to accept incorrect statements. This tendency was present in both groups and thus it does not compromise the results.

PREDICTORS OF AD KNOWLEDGE

Based on the six preliminary regression equations, six variables were entered into the final regression equation for scores on the open-ended questions. Two variables significantly predicted comprehension and accounted for 16% of the total variance in the final equation: younger patients ($R^2=.04$; $\beta=-.13$) and those with more education ($R^2=.12$; $\beta=.39$) were more likely to have greater overall comprehension. Based on the six preliminary regression equations, nine variables were entered into the final regression equation for scores on the yes-no questions. Two variables significantly predicted comprehension and accounted for 17% of the total variance in the final equation: younger patients ($R^2=.11$; $\beta=-.26$) and patients who had longer informal AD-relevant discussions with their physician ($R^2=.07$; $\beta=.32$) had greater overall comprehension.

COMMENT

The results of the present study show that (1) patients in the AD and HP discussion groups did not differ on the open-ended or yes-or-no comprehension question tests and (2) the level of comprehension in both groups was quite good (eg, about 80% correct on yes-or-no questions). That patients' comprehension was not improved by short, prepared discussions with the physicians suggests that the comprehension test measured preexisting knowledge of AD-related information rather than information recently acquired from the physicians' discussions. The high level of this preexisting knowledge suggests that, even in the absence of explicit explanations by physicians, older adults have a reasonable working

knowledge about ADs, CPR, and ANH on which to base preferences for life-sustaining treatments.

Both of these results are similar to findings by Schonwetter et al,¹⁶ who found that older adults exhibited a high level of basic knowledge about CPR that did not change with an educational intervention. Interestingly, the subjects in the study by Schonwetter et al initially overestimated their chances of survival, with these estimates decreasing toward more realistic levels after the educational intervention. An improved understanding of quantitative outcome data, therefore, could influence the desire for CPR by reducing its perceived effectiveness, suggesting that outcome information should be included when discussing CPR with older adults.

Some patient characteristics and certain aspects of the discussion did moderate patients' production of AD-related knowledge. First, older patients had less knowledge of AD-related information. This result is similar to findings by Ley and Spelman,⁶ who report a negative relationship between age and recall of medical information. Second, scores on the open-ended questions were lower the less education the patient had completed. These results suggest that physicians need to be sensitive to age and education level when discussing AD-related issues with patients.

Third, scores on the yes-or-no questions were lower the less time the physician spent talking with his or her patient about AD-related issues after the discussion based on the prepared script was completed. The causal direction of this relationship is not certain. Perhaps patients who have a poor working knowledge of AD-related issues beforehand are less able to discuss these issues effectively with their physician. If so, physicians and patients should attempt to create a common ground that includes shared information about ADs, CPR, and ANH.³²

The posttalk discussion primarily centered around the value patients place on their functional capacity. In response to a final open-ended question as to whether patients could think of any illness or condition in which they would not want their life prolonged, 42% responded with a specific illness or condition such as coma, Alzheimer's disease, or stroke. However, 57% emphasized functional status (eg, "As long as I had my mind" or if I am "not mentally able") even though illness, and not function, was the focus of the question. These patients spontaneously mentioned the importance of being able to engage in valued activities. Advance directive documents and discussions should be designed to gather information about the patients' treatment preferences in terms of functional outcomes in addition to preferences based on specific illnesses and conditions.³³

There were several possible limitations of the present study. First, the relatively small sample size of the HP discussion group makes it possible that there was insufficient power to detect between-group differences. The post hoc power analysis for the comparison based on yes-or-no questions, however, indicated that there was adequate power to detect differences between the groups. Even though the AD group produced slightly more correct open-ended responses, the HP group was slightly

more accurate on the yes-or-no questions. Therefore, it seems unlikely that a population difference is being masked by the lack of sufficient power.

Second, the information the physician provided to the patient was prepared for reasons of experimental control. However, physicians were encouraged to paraphrase the prepared script in their own words and to elaborate in response to patients' questions. The effectiveness of such elaboration was demonstrated by the result that subsequent AD-relevant discussion predicted better comprehension. The script tended to focus on mechanisms of life-sustaining treatment rather than on effectiveness. Physicians may want to consider discussing issues other than the mechanics of treatment.

Third, the high test scores may have been owing to a relatively easy comprehension test. Alternatively, these scores may reflect a relatively high general knowledge since the AD group had sufficient knowledge to adequately voice their preferences about life-sustaining treatments.

Fourth, patients may have had a bias to respond yes to the yes-or-no questions since most of the incorrect responses were on no questions, and 61% of the responses to all questions were yes. However, there were no differences between the two groups on the yes-or-no questions.

Fifth, patients were volunteers willing to participate and so constitute a special group. However, potential patients did not know the study was about ADs, so the sample was not biased to include patients with special knowledge about or interest in ADs, CPR, or ANH.

CONCLUSIONS

This study found that elderly outpatients have sufficient knowledge about ADs, CPR, and ANH to voice preferences about life-sustaining treatments. Younger and better-educated patients demonstrated greater knowledge. Patient knowledge was not improved by a physician-initiated AD discussion using a prepared script. However, increased amounts of time spent by the physician and patient after the AD discussion were associated with greater AD knowledge. Physicians' awareness of these factors may enhance their effectiveness in discussing AD-related issues with elderly patients.

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Reprint requests to Department of Psychology, Kent State University, Kent, OH 44242 (Dr Danks).

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