Promoting Advance Directives Among Elderly Primary Care Patients

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OBJECTIVE: **To determine efficient ways of promoting advance directives among heterogeneous populations of elderly ambulatory patients.**

DESIGN: **One-year quasi-experimental trial.**

SETTING: **Five suburban and urban health centers in one region of a large managed care organization. One additional suburban center served as a control site.**

PARTICIPANTS: **Individuals ages 65 and older (*N* = 2,120) who were continuously enrolled and had a health maintenance visit with their primary care provider during the study year.**

INTERVENTION: **Physician education (oral and written) and physician and patient prompts to discuss advance directives.**

MAIN RESULTS: **Sixty-six (7.8%) of patients at the intervention centers completed new advance directives, versus 9 of 1,277 (<1%) at the comparison center (*P* < .001). Patients 75 and older were twice as likely (odds ratio [OR], 2.0; 95% confidence limits [CL], 1.2 to 3.3) as those 65 to 74 to file a new advance directive, and the odds were twice as great (OR, 2.6; 95% CL, 1.4 to 4.6) at centers serving communities with median household income over the state median. Gender, recent hospitalization, emergency room visits, and number of chronic conditions were not related to making new directives nor was predominant ethnicity of the center community (African-American versus white). Adjusted for these factors, the intervention resulted in a 20-fold increase (95% CL, 10.4 to 47.8) in the odds of creating a new advance directive. Doctors reported barriers of time and unwillingness to press discussions with patients.**

CONCLUSIONS: **A replicable intervention largely targeting doctors achieved a modest increase in advance directives among elderly ambulatory patients. Future interventions may need to target lower-income patients, "younger" elderly, and more specifically address doctors' attitudes and comfort discussing advance directives.**

KEY WORDS: **advance directives; primary care; elderly; ethnicity; income.**
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Advance directives (durable powers of attorney, values history statements, living wills) are considered to be important tools for promoting patient autonomy, dignity, reassurance, and empowerment.[1,2] However, only about 15% to 25% of adults complete advance directives.[1,3,4] Many do not do so until they are hospitalized with a serious illness, when time may not allow conferring with family members or with long-time medical providers.

Surveys find that most adults would prefer to discuss advance directives while they are well, preferably with a doctor who has known them over time.[3,5–8] Most also say they look to their doctors to initiate the discussion.[5,9,10] A study of ambulatory managed care patients 65 or older found that a doctor's inquiry increased two- to three-fold the chances that individuals would have an advance directive on file with their health plan.[11]

Attempts to increase the proportion of ambulatory, elderly individuals who create advance directives suggest both opportunities and barriers. Three studies directed primarily toward patients achieved modest success using printed materials distributed by mail. The most successful used a combination of a carefully designed pamphlet and a form to create a durable power of attorney.[12] Nearly 17% of those 65 to 74, and 20% of those 75 and older, created a new durable power of attorney, compared to less than 1% of those in a randomized control group. The target population was over 70% white and composed of individuals who had had at least one hospitalization in the past year. The proportion of African Americans and Hispanic Americans completing advance directives was smaller than the proportion among whites.[12,13] A study in a center-based health maintenance organization found that about 14% of patients 75 and older, not selected for having been hospitalized, made a new advance directive in response to a mailed pamphlet and form.[14] In contrast, a study in a predominantly white, low-income population found that printed materials alone did not promote the creation of new advance directives, but that a group meeting resulted in 25% making a new "living will."[15]

Studies targeting doctors have also met with mixed success. A 5-week training program, with permission to use extra time to discuss advance directives, was initially not sufficient to motivate doctors working in a nursing home and home care program.[9] However, modeling by the investigators (demonstrating the discussion with a series of each doctor's own patients) resulted in 65% of home care and 90% of nursing home patients making a new advance directive. Two much less intensive interventions in primary care settings resulted in smaller changes. The most simple involved computerized reminders for doctors seeing either well elderly (75 or older), or younger patients with serious illnesses.[16] Fifteen percent of patients whose doctors received reminders, compared to 4% in a control group, made new advance directives. Another intervention aimed at doctors

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involved a brief training session, printed materials for the doctor to hand out, and telephone follow-up.[17] Fifteen percent of patients whose doctors received all components of the intervention made new advance directives (living wills), while none did among a group given only written material.

Thus, the most successful advance directive programs targeted patients who had the greatest possibility of seeing themselves at risk (recently hospitalized, older, already receiving specialized care), and involved fairly intensive training for doctors, including modeling of discussions with patients. Reminders for doctors seemed capable of promoting more modest increases in advance directive rates. In addition, mailed materials seemed to be effective when distributed in middle-income settings, but personal interaction (in the form of group sessions or doctor-initiated discussions) was needed among lower-income patients.

Our goal in this study was to see whether it was possible to increase the use of advance directives among a socioeconomically heterogeneous group of ambulatory, elderly patients. The study took place in 5 medical centers belonging to a single managed care organization (MCO), and our main outcome measure was the number of patients newly filing an advance directive with the MCO during the study period. We elected an approach based largely on changing doctor behavior, but with prompts to patients. The doctor behavior we targeted was initiation of a discussion of advance directives during health maintenance visits.

Our decision to focus on doctors rather than patients was based on several factors. First, as noted above, several studies have found that patients say they would prefer to discuss the topic with their own doctor and would like the doctor to raise the subject. Second, we were concerned that it would be difficult to produce a single form of written material that would address a wide range of literacy and knowledge needs.[8,13] In addition, despite the success of mail interventions by other managed care organizations,[12,14] we were concerned that the materials might be misperceived. Surveys have found that while their confidence levels are high, patients of managed care organizations are less certain than fee-for-service patients that their doctors will put medical concerns above financial considerations.[18]

METHODS

Design

Prospective, quasi-experimental (nonequivalent control group).[19]

Setting

The intervention took place in the Baltimore area medical centers of the Kaiser Permanente Medical Group (KP). The 5 Baltimore centers are located downtown (1) and in suburban communities (4) and serve a total population of about 50,000. The comparison center, which served as a nonequivalent control group, is located in the Maryland suburbs of Washington, DC and serves a patient population of about 42,000. All study centers are in the same state and subject to the same laws about advance directives.

KP does not collect ethnicity or income data from enrollees, but it is possible to compare data about the communities served by each clinical site. The comparison center served a relatively affluent community that is 6.1% African-American, 8.4% Hispanic or Latino, and that had a median household income in 1999 of $81,906. The statewide median household income is $52,868.[20] The intervention center communities all had Hispanic/Latino populations of 2% or less, but the proportion of African Americans ranged from 2.5% to 73.3%, and the median household incomes ranged from $16,148 per year to $65,311 (Table 1).

Population (Patients)

The majority of KP members receive their health insurance coverage via their employer, or are retirees from their former employer. At the beginning of the 1-year study period, a total of 8,397 individuals who would turn 65 or older during the study year were enrolled in one of the 5 Baltimore-area centers or in the comparison center (age range 64 to 105, mean 71.1). To evaluate the impact of the study intervention, we retrospectively examined records of 2,120 who 1) were continuously enrolled for the study period, and 2) who had had a scheduled, "extended health maintenance visit" (a 45-minute visit intended to cover both preventive care and chronic issues) during the study year. KP protocol calls for elderly patients to have one of these extended visits every 2 years, in addition to any needed acute or follow-up visits.

Population (Doctors)

Across centers, providers of each specialty form departments that meet monthly, coordinated by a chief and the area's overall medical director. We worked with the area department of internal medicine, staffed by 22 internists, 2 family physicians, and 5 certified nurse practitioners. Within sites, providers have their own panels of patients.

Patient Intervention

Patients scheduled for an extended health maintenance visit received a reminder letter asking them to bring any current medications and copies of any advance directive they might have. The letter said, "Your Kaiser health care team believes that talking about end of life decision-making is an important part of a complete health assessment," and referred to the advance directive section of a health maintenance handbook given to all patients and a "Planning Ahead" brochure on display in all waiting areas.

Table 1. Differences Among Intervention Centers—Continuously Enrolled Members 65 or Older at the Start of the Study Who Had at Least One Health Maintenance Visit

	Downtown	Suburban 1	Suburban 2	Suburban 3	Suburban 4	Significance
Center characteristics						
Number of studied enrollees	36	62	176	386	182	—
Female, %	58	55	54	42	52	.013
Mean age, y	70	69	70	70	70	.09
>2 chronic EDC, %	31	13	21	13	20	.01
One or more ER visit, %	17	15	20	8	23	<.001
One or more hospitalization, %	3	2	6	3	2	.35
Community served*						
African American, %	62	5	3	6.0	73	—
Median household income, $	16,148	61,452	65,311	53,534	44,359	—
Advance directive results						
Number with AD prior to study (%)	0 (0)	0 (0)	12 (7)	3 (1)	8 (4)	<.001
Number of ADs added during study (% of eligible)	2 (6)	10 (16)	21 (12)	22 (6)	11 (6)	.009
Number of ADs at end of study period (% of eligible)	2 (6)	10 (16)	33 (20)	25 (7)	19 (10)	<.001

** 2000 U.S. Census data for zip code tabulation areas (ZCTA) where clinic is located.*
AD, advance directive; EDC, expanded diagnostic clusters; ER, emergency room.

After the visit, enrollees received a follow-up letter restating KP's encouragement to discuss advance directives. Both letters were signed by the area chief of internal medicine (see Table 2).

Provider Intervention

The area chief led the provider intervention, which was designed around recommendations for promoting changes in doctors' behavior, including endorsement by an opinion leader, personalized outreach, feedback of results, and organizational change to support the doctors' change.[21]

The chief made a single presentation to the internal medicine staff as a whole, and then at each of the 5 intervention sites she presented the project to core clinic staff (nursing, registration, record keeping). Presentations outlined the rationale for the effort, the organization of materials to prompt doctors, and how KP was organizing its data systems so that advance directives would be available for urgent care.

Doctors received a "desk book" including a summary of the 1990 Patient Self-determination Act, sample scripts for discussing advance directives, answers to common patient questions, and samples of a durable power of attorney for health care, a "living will," and a health care values checklist. Two assessment "cue cards" covered the influence of depression and dementia on advance care decision making.

Table 2. Summary of Intervention Components*

Patient components
  Pre- and postvisit reminder letters
  "Planning Ahead" brochure and chapter in health maintenance "handbook" (in place prior to intervention and also available at control center)

Provider components
  Presentations to medical and support staff by chief of internal medicine
  "Desk book" with interaction scripts, responses to questions frequently asked by patients, and assessment tools for commonly occurring complicating problems (dementia, depression)

Organizational components
  Health maintenance task checklist attached to extended health maintenance visit charts by clinic support staff (includes asking about advance directive)
  Preprinted sticker to remind provider to reintroduce issue at subsequent visit
  Enhanced availability of advance directives via scanning and storage on central computer

Reinforcement steps
  Single follow-up visit to providers by research assistant
  Weekly follow-up visits to support staff by research assistant
  Monthly feedback by site of number of new advance directives collected

** See text for details.*

Organizational Intervention

Office personnel stamped patient encounter forms with a checklist of health maintenance tasks, including discussing an advance directive.[16] Also clipped to the form was an optional flow chart for documenting advance directive discussions and a preprinted adhesive note to prompt follow-up at a subsequent visit.

Reinforcement

A research associate visited each doctor shortly after the start of the project to ask whether the materials were helpful or needed clarification, and made weekly trips to each intervention site to confer with nursing and administrative staff. Statistics were collated monthly and fed back to clinic managers. Clinics with the best performance received a pizza lunch for its staff, served by one of the regional administrators.

Evaluation Data Sources

Patient demographics, diagnoses, and baseline advance directive status (on file or not) were obtained from computerized records. These records were searched to identify individuals whose advance directive status (on file or not) had changed during the study year. The International Statistical Classification of Diseases and Related Health Problems, tenth revision (ICD-10) codes reflecting patient diagnoses at each visit were categorized using Expanded Diagnostic Clusters (EDCs), a component of the Johns Hopkins University Adjusted Clinical Group (ACG) case-mix classification system.[22] EDCs were further grouped into chronic and acute. In our analyses, we compared patients who had fewer than 3 chronic conditions with those who had 3 or more.

Following the provider training, a research assistant (not the one who had regularly visited the study centers) called each participating physician and conducted a brief (8-question) semistructured debriefing interview. To promote candor, no information identifying doctors or their work site was collected, and calls were not recorded. The assistant noted provider answers in short phrases and summarized the responses to each question.

Statistical Analysis

In this study, the allocation of patients to intervention and control status occurs at the regional level, and there are essentially only two “clusters” of patients, those in the intervention and those in the control group. Thus, controlling for intervention status could be seen as the sole adjustment required in our analyses. However, for analyses of differences among the intervention sites, patients are clustered within clinics and, within clinics, by provider. For these analyses, we used logistic regression models calculated using generalized estimating equations (GEE; Stata 6, STATA Corporation, College Station, Tex), with provider as the clustering variable and with intervention sites represented as dummy variables.

Human Subjects

The intervention program was approved by the Kaiser Foundation Research Institute Institutional Review Board, and was presented for comment to the members’ regional advisory board of the Kaiser Foundation Health Plan of the Mid-Atlantic States, Inc. The plan for evaluation of the intervention was additionally approved by the Committee on Human Research of the Johns Hopkins School of Public Health.

RESULTS

Baseline Differences Between Intervention and Comparison Centers

Of 2,120 patients followed for the evaluation, 842 received care from one of the 5 intervention centers and 1,278 from the comparison center. Patients at the comparison center were more likely to be female (54% vs 48%; $P < .01$) and were slightly older (mean 71.4 years old vs 70.3; $P < .001$; Table 3). Twenty-three percent of comparison center patients had more than 2 chronic EDC conditions, versus 17% among intervention center patients ($P = .001$). At the start of the intervention period, 94 (7.4%) of comparison center patients were known to have advance directives, compared to 23 (2.7%) of intervention center patients ($P < .001$).

Table 3. Differences Between Intervention Centers (as a Group) and Comparison Center: Continuously Enrolled Members 65 or Older at the Start of the Study Who Had at Least One Health Maintenance Visit

Descriptor	Intervention (*n* = 843)	Comparison (*n* = 1,277)	Significance
Female, %	48	54	<.01
Mean age, y	70.3	71.4	<.001
>2 chronic EDC conditions, %	17	23	.001
One or more ER visit, %	15	18	.09
One or more hospitalization, %	3	5	.16
Number (%) with AD prior to study	23 (2.7)	94 (7.4)	<.001
Number of ADs (%) at end of study	87 (10.3)	100 (7.8)	.048

AD, advance directive; EDC, expanded diagnostic clusters; ER, emergency room.

Table 4. Factors Associated with Adding an Advance Directive During the Study Period: Continuously Enrolled Members 65 or Older at the Start of the Study Who Had at Least One Health Maintenance Visit

Factors	Number of New Advance Directives (%)	*P* Value
Age, y		
<75	43/1451 (3.0)	.035
≥75	32/669 (4.8)	
Gender, %		
Female	40/1099 (3.6)	.79
Male	35/1021 (3.4)	
Hospitalized during study year, %		
Yes	0/86 (0)	.07
No	75/2034 (3.7)	
Emergency room visit during study year, %		
Yes	9/350 (2.6)	.28
No	66/1770 (3.7)	
EDC chronic conditions, %		
3 or more conditions	13/441 (3.0)	.45
0–2 conditions	62/1679 (3.7)	
Study status of clinic site, %		
Intervention	66/843 (7.8)	<.001
Control	9/1277 (0.7)	

EDC, expanded diagnostic clusters.

Patient Characteristics Associated with Making a New Advance Directive

During the study period, 75 of the 2,120 (3.5%) patients followed at the control and intervention centers filed new advance directives. Of these, 70 of the 75 (93%) were made by patients who did not have one previously on file.

Patients 75 or older were more likely to make a new advance directive than patients 64 to 74 (4.8% vs 3.0%; *P* = .035; Table 4). Age was only a factor among the intervention center patients, however. The rate of new advance directives among intervention center patients was 6.4% for patients 64 to 74, 11.3% for patients 75 to 84, and 13.0% for patient 85 and older (*P* = .047).

Patient gender was not significantly associated with making a new advance directive. Overall, 3.6% of women made new advance directives compared to 3.4% of men (*P* = .79).

No measures of medical severity (admission to hospital, emergency visits, and number of chronic conditions) were related to making an advance directive in the study year. Eighty-six (4.1%) of the 2,120 patients were hospitalized at least once during the study period, but none of these patients made a new advance directive. Of 350 patients (16.5%) who made at least 1 emergency visit in the study year, 2.6% made a new advance directive, compared to 3.7% of those who did not make an emergency visit (*P* = .28). Of 441 patients (21%) who had 3 or more EDC chronic conditions, 3.0% made a new advance directive, compared to 3.7% of those with fewer than 3 conditions.

Overall Effect of the Intervention

During the study period, 66 (7.8%) of the 843 patients at the intervention centers made new advance directives, compared to 9 of 1,277 (0.7%) at the comparison center (*P* < .001). By the end of the intervention, 87 (10.3%) of intervention center patients had advance directives on file, compared to 100 (7.8%) at the comparison center (*P* = .048).

Because there were differences between the intervention and comparison populations at baseline, we used multiple logistic regression to calculate an adjusted estimate of the increased odds that patients at the intervention centers would have an advance directive added (Table 5). Patients at the intervention centers had a 22.3-fold increase (95% confidence limits [CL], 10.4 to 47.8) in the odds of adding an advance directive versus the comparison center, and patients 75 and older had a two-fold increase (95% CL, 1.2 to 3.3). Gender, number of chronic conditions, and having had an emergency room visit were not associated with having made a new advance directive. Community income was significantly associated with making an advance directive (odds ratio [OR], 2.6; 95% CL, 1.4 to 4.6), but community ethnicity was not.

We also explored characteristics of intervention providers that might have explained the variation in response among intervention center patients. Neither provider gender (male vs female, OR, .73, 95% CL, .44 to 1.19), specialty (internal medicine vs others, OR, 1.87, 95% CL, .66 to 5.31), nor professional degree (MD vs nurse practitioner, OR, 4.06, 95% CL, .54 to 30.64) was related to whether or not patients completed a new advance directive during the study period.

Provider Follow-up Survey

About half the participating providers said they lacked time to discuss advance directives with patients, despite

Table 5. Logistic Regression Results: Factors Associated with Creating a New Advance Directive During the Intervention Period

Factor	Odds Ratio	95% Confidence Limits
Intervention vs comparison center	22.34	10.4 to 47.8
Age 75 or greater vs 65 to 74	2.00	1.2 to 3.3
Male gender vs female	.91	.56 to 1.5
3 or more chronic conditions vs 0 to 2	.88	.47 to 1.7
At least one emergency visit versus none	.72	.35 to 1.5
Center community ethnicity (white vs African American)	.91	.44 to 1.9
Center community median household income (above vs below state median)	2.68	1.4 to 4.6

the availability of extended health maintenance visits. Problems with time seemed to center on three issues: the need to provide more guidance to patients who had difficulty understanding advance directives, questions about who in the health care system was best suited to discuss advance directives, and concerns about system priorities. Difficulties arose if low-literacy patients, or those who were not familiar with the concepts behind advance directives, needed more than fairly simple explanations. Some providers said they felt that going into more elaborate explanations went beyond their responsibility, and suggested that perhaps a social worker or nurse might be more appropriate. Some providers felt that specialists—especially those involved with the care of serious chronic conditions—had more time and knowledge to bring to the task. Other providers intimated that while they felt that discussing advance directives was a part of their job, it was the responsibility of others—patients themselves, or the clinic management through the placement of brochures and other educational means—to raise the subject. One common opinion was that aspects of care such as completing advance directives and making follow-up telephone calls to check on patients' progress were important aspects of good medicine, but not truly encouraged by practice leadership because they were not factored into ratings of provider productivity.

All providers reported that some or all of the written study materials were useful (in particular, reminder stickers to cue discussion at future visits), but several thought that the study training session was not needed. Explanations for this opinion included feeling that they did not need to be convinced of the importance of advance directives, and that the study's written materials were "self-explanatory." Other providers suggested that instead of a didactic session, practice in actually having the advance directive discussion with patients would have been helpful. These providers again underlined that they did not need to be convinced that advance directives were important, but felt they lacked skills related to talking about them with patients. Some said they were more comfortable if patients initiated the advanced directive discussion, and others said that they did not feel comfortable "belaboring" the issue if patients seemed uninterested or reluctant.

DISCUSSION

A largely doctor-based brief intervention was able to increase the proportion of ambulatory, elderly patients who had an advance directive on file with their doctor. The overall increase was modest but similar to that reported in prior studies. Dexter et al.[16] found that computerized reminders to doctors resulted in about 15% of patients 75 and over completing advance directives, compared to 4% among patients of doctors who did not receive reminders. In our study, 11% of intervention patients 75 or over made new advance directives, compared to about 1% in the comparison population.

As in prior studies, we found that patient age was related to making a new advance directive.[12,16] The relationship with age could be a function of both patient and doctor factors. In Rubin et al.'s study,[12] which was directed to patients, increasing age was associated with greater response. Surveys of doctors find that doctors think it more appropriate to approach older patients.[5] Unfortunately, in our evaluation, we do not have reliable information on how frequently and with whom doctors raised the issue of making an advance directive. The lack of a relationship with health status seems to contradict the fact that studies of recently hospitalized or nursing home patients have achieved higher levels of advance directive creation.[9,12] It may be that by targeting our intervention to individuals making health maintenance visits we excluded those with more serious illnesses—less than 5% had been hospitalized in the past year.

One important interpretation of our results is that they may demonstrate the limits of what can be accomplished with relatively simple organizational and educational interventions. Despite reminders, ready access to materials, and a focus on extended-length visits designed for preventive as well as follow-up care, providers still felt they lacked time and reported reluctance to pursue discussions of advance directives. We evidently did not do enough to help doctors overcome concerns about other demands on their time with patients, or to help them feel competent to pursue discussions with hesitant patients or those with many questions. Studies of how mental health problems are handled in primary care demonstrate similar barriers.[23,24] Although we included scripts and guides for advance directive discussions and related evaluations, and prepared answers to common patient questions, passive exposure to these materials was not sufficient. As Markson et al. found in their study of advance directives,[9] and as others have noted in other aspects of physician behavior change, active modeling and practice of new skills may be required.[25,26] Indeed, some providers said they would have liked to have had this kind of training.

Another limit of our intervention may have been the extent to which it was or was not seen as an institutional priority. Although the main educational session for providers was presented by the area chief of internal medicine, follow-up "detailing" sessions[27] were by a research assistant rather than a medical professional. Monitoring and feedback may also not have been perceived as sufficiently serious, and providers noted that advance directive rates were not considered in assessments of their productivity.[21] Although we gave centers feedback on their performance relative to each other, and the reward of a catered lunch was helpful in securing the essential collaboration of support staff, advance directives were not part of the panel of quality indicators used by KP administrators in their formal assessments of center or provider performance.

Our results also suggest that there are barriers posed by patient socioeconomic status. The highest proportion of new advance directives, and the highest proportion of elderly patients with advance directives, was achieved at centers serving communities whose median household income was above the state median. In contrast, we did not find significant variation attributable to community ethnicity. Further studies might show whether socioeconomic differences in discussion of advance directives are related to differences in provider attitudes, patient attitudes, or both. Providers may be uncomfortable or lack skills to raise sensitive topics with patients of a different socioeconomic status, and low-income or minority patients may feel less trusting that providers will act in their best interests.[28,29] In our discussions with providers, patients' general and "health" literacy also came up as barriers. Some providers did not feel that they had time to address very basic questions about the concepts involved in creating an advance directive. They may thus have either avoided or put off advance directive discussions with patients who they feared might have too many questions. Providers suggested that some patients could have used assistance from nurses or social workers to help them understand the legal and medical issues involved prior to a discussion with their physician.

A major limitation of our evaluation is that we know little about the mechanism by which the intervention had its effect. We do not know how frequently advance directives were actually discussed, who raised the discussion, what kinds of directives were proposed to patients, how the discussion was framed, or if resulting directives were truly "new" or represented notifying the provider about one that already existed. What is encouraging, however, is that the intervention was able to bring the overall rate of advance directives among the intervention centers—which serve low- and middle-income communities—up to and slightly higher than that of the comparison center—which serves a community that is markedly more affluent than the state average.

In conclusion, a relatively simple intervention, largely targeting doctors, modestly increased the proportion of elderly ambulatory patients who had an advance directive on file with their primary care provider. Some components of the intervention—including doctor and patient reminders and performance feedback to clinical sites—could be readily automated and thus sustained over long periods of time. A more intensive intervention with doctors, possibly including active modeling of and practice talking about advance directives, plus more formal monitoring and feedback, may be necessary to achieve higher response rates. The highest response rates were observed in centers serving communities with the highest income, suggesting that additional measures will be needed to address the needs and concerns of low-income patients.

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