Promoting the Use of Advance Directives

An Empirical Study

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Objective: To examine the effects of a practical method to increase patient completion and filing of advance directives.

Methods: Randomized controlled trial to examine the effects of structured discussions, information, and mailed reminders on completion of advance directives by internal medicine outpatients.

Main Outcome Measure: Presence of advance directives in patients' medical files. Secondary analyses include (1) participant satisfaction with procedures, (2) data on delayed effects of discussion, and (3) data on discrepancies in patients' completion of forms.

Results: Six months following the intervention, 23% of patients in the experimental group and 3% of patients in the control group had directives on file. The findings were statistically significant. Patients, nurses, and physicians were satisfied with intervention procedures. Chart reviews at 6 weeks and 6 months indicated that intervention effects were delayed.

Conclusions: Structured discussions and follow-up mailings substantially increased use of advance directives and were time effective and cost-effective.

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Researchers from the University of Kansas, Lawrence, and the University of Kansas School of Medicine–Wichita collaborated with members of Kansas Health Ethics, Wichita, on the design and implementation of this study. Kansas Health Ethics, as part of its mission, sought to increase the numbers of persons who executed advance directives. The project developed forms, provided workshops, and encouraged discussion between health care and legal professionals and their patients and clients. This research was conducted as part of an effort to identify effective protocols for promoting widespread use of advance directives.

Dying is a complex process. The past 50 years have brought changes in medical technology, laws regarding treatment and liability, and health care costs. Increasingly, the manner and timing of death is determined not by fate but by decisions made by loved ones, caregivers, and courts.1

Although many people report that end-of-life decision making is important, few have completed written advance directives.2 A 1991 Gallup poll3 found that 75% of respondents would like to have, in the future, a living will. Fifteen percent of respondents reported that they had completed a living will. This figure is much higher than rates of completion found in other recent studies, which range from 2% to 7% prior to intervention.4,5 Low rates of use may be owing to lack of information and/or accessibility of forms, discomfort in discussing death and dying, or uncertainty regarding the benefits of completing an advance directive.

The federal Patient Self-determination Act (PSDA), effective in December 1991, requires hospitals, nursing homes, and other health care providers to ask patients whether they have advance directives, include any existing directives in the medical record, and help guide the implementation of directives.6 Patients can now use a myriad of forms to document their treatment choices in case they become terminally ill or are unable to communicate their wishes.

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PATIENTS AND METHODS

DESIGN

This study used a randomized controlled trial to assess the effects of discussion and a follow-up mailing on completion and filing of advance directives. Patients visiting the practice over a 10-day period were assigned to experimental (n=87) and control (n=89) groups, according to whether each patient's medical record number ended in an odd or even number. Although not true random assignment, this method of grouping participants probably resulted in randomly distributed groups, since clinic numbers are assigned consecutively. All patients in the experimental group received a discussion with a physician; preaddressed, stamped materials; and a follow-up mailing. Patients in the control group received a brochure on advance directives only. The main outcome measure was the presence of advance directives in patients' medical files 6 months after the intervention.

DEVELOPMENT OF THE DISCUSSION COMPONENT

Before the study, two of us (K.P.R. and S.L.) developed guidelines (Figure 1) for physicians to use when discussing advance directives with patients. Although the guidelines were primarily designed to remind physicians what key aspects should be pointed out to patients, they also were introduced to enhance uniformity of the independent variable. The guidelines were developed using a literature review and a task analysis of a videotaped discussion between a patient and an experienced physician.5,13-16

TRAINING OF NURSES AND PHYSICIANS

One week before the intervention, three of us (K.P.R., S.L., and R.M.) conducted training sessions for nurses and physicians briefly describing the purpose and design of the study, the role of nurses and physicians, and the guidelines and data sheets they were to use with patients. All the nurses and physicians in the clinic participated in the training and intervention.

INTERVENTION

During the 10-day intervention period, researchers assigned patients to groups and attached the discussion guidelines sheet and advance directives materials to the outside of charts. On entering the examining room, physicians greeted the patient, conducted the discussion, collected data, and handed the patient materials on advance directives before conducting the physical examination. The packet of material included legal forms for a living will and a durable power of attorney for health care decisions. Physicians were asked to suggest that the patient fill out one or both directives, keep the original, and send a copy to the practice. (Copies of the Wichita Advance Directives form and study materials are available from the authors on request.)

Approximately 2 weeks after the discussion, investigators mailed additional materials to patients in the experimental group. Materials included (1) a cover letter, (2) brief descriptions of five life-sustaining treatments,15 (3) an addressed, stamped survey to be completed and returned, (4) a blank copy of an advance directive, and (5) an addressed, stamped envelope to return the directive to the clinic. The cover letter was addressed to each patient personally and closed with a thank-you from that patient's physician. The letter suggested that the patient fill out the survey and advance directive form and return both by a given date.

Investigators kept the costs of the intervention to a minimum, reasoning that lower costs might enhance the likelihood that the procedures (if effective) would be adopted by other providers. Materials for the intervention, including printed matter and postage, cost approximately $220.

CONTROL GROUP

During the intervention period, patients assigned to the control group received an advance directive form from a nurse who suggested that they take the form home, look it over, evaluate the effectiveness of physician consultation on completion of advance directives.

One study explored the effects of two patient-physician discussions on patients' completion of advance directives.10 Following the intervention, 64% of patients had completed durable powers of attorney. Since patients were not randomly selected for participation, and since there was no comparison group, we cannot be certain that the sizable effects can be solely attributed to the patient-physician discussions.

Sachs et al11 conducted a randomized clinical trial to examine the effects of a patient-physician discussion and handout materials on older adults' completion of advance directives. The intervention provided the following three components: (1) a 20- to 30-minute discussion using examples of treatment scenarios, (2) blank advance directive forms, and (3) reminder cards to encourage patients to discuss treatment wishes with their
and return a copy to the clinic if they chose to complete it. This is the usual method of distributing advance directives in the clinic. Physicians were asked to complete a data sheet (affixed by researchers to the outside of the chart) before the physical examination.

PATIENTS AND SETTING

A university-based internal medicine practice, located in a medium-sized midwestern city (population, 280,000), provided the setting for this research. Each of the three attending and 15 resident physicians had his or her own patients. Patients scheduled appointments and saw the same physician at each visit.

The participants were patients over 18 years of age who visited the practice over a 2-week period. The patient base is diverse, including Hispanic, Asian, and African-American persons. Attending physicians have long-standing practices serving middle-income patients. The practice serves many geriatric patients and patients with acquired immunodeficiency syndrome. Approximately 15% of the patients have no form of insurance. The physicians conducted the discussions as a part of routine office visits scheduled by the patients themselves for health checkups or physical complaints.

A total of 176 patients participated. Of 110 persons assigned to the experimental group, 19 refused to participate, and four were excluded from the study on account of extreme emotional or physical distress, leaving a total of 87 patients. Eighty-nine patients were assigned to the control group.

Patients assigned to the experimental group were informed of the nature of the study and signed consents to participate. The study design, content, and consent forms used were reviewed and approved by human experimentation committees of the University of Kansas, Lawrence, and University of Kansas School of Medicine-Wichita.

DATA COLLECTION AND MEASURES

Patients’ completion and filing of advance directives were observed by reviewing their medical charts for information on (1) demographic background of participants, including age, marital status, and insurance status; (2) the presence or absence of any form of advance directive; and (3) data on any form of advance directive present, including the date and sponsoring agency of the directive and which sections of the directive were completed.

Researchers and physicians collected additional information not normally available in a chart review. From members of the experimental group, researchers and physicians collected data on race, ethnic background, educational status, overall health status, and the length of the patient-physician discussion. From patients in the control group, physicians collected data on overall health status and race.

Once completed, all data study sheets were inserted in the charts for retrieval by investigators during the chart review conducted approximately 6 weeks after the discussions. The postintervention chart review was conducted approximately 6 months following the discussions.

In addition, the authors surveyed patients and staff to find out whether the goals, procedures, and outcomes of the study reflected the needs and interests of participants. The survey used a five-point Likert scale to record a range of possible responses, from 1 (least favorable) to 5 (most favorable). Physicians and nurses completed surveys at the training session and after the intervention. Patients received surveys in the follow-up mailing.

ANALYSIS

Three statistical tests were used to examine differences between groups in the study. The differences in proportions test was used to examine differences between the number of patients with advance directives on file before and after the intervention. The pooled-variance t test and analysis were used to examine potential differences in the demographic characteristics of the experimental and control groups. An α level of .05 was used as the cutoff for rejection of the null hypothesis. Bonferroni adjustments for multiple statistical tests were made to the cutoff.

physicians. Investigators reviewing patients’ charts 6 months later found no statistically significant difference in experimental and control groups.

Another study used a randomized clinical trial with measures taken only after the intervention to examine the effects of materials and physician contact on patient execution of advance directives. A 30-minute interview, repeated patient-physician discussions, and an offer of a free clinic visit achieved a 15% completion and filing rate in the experimental group.

Physician time is a precious commodity. Two studies have examined the use of a less costly form of intervention, personalized mailings, to increase completion of advance directives. High examined the effects of printed materials and invitations to information workshops on completion of advance directives. Study participants received packets of materials from investigators. Materials consisted of little, moderate, or large amounts of printed matter, either with or without an invitation to a workshop. A moderate amount of materials together with an invitation produced a statistically significant increase in self-reported completion of advance directives.

A randomized controlled trial examined the effects of mailed information and forms on completion of durable powers of attorney for health care. The participants were 1101 patients aged 65 years and older who had been discharged from a hospital over a 5-month period. Following intervention, 18% of persons in the experimental group and 0.4% of persons in the control group had a durable power of attorney for health care on file.

We examined the effects of three kinds of assistance on patient completion and filing of advance directives. Components were (1) a structured discussion with a physician, (2) provision of blank, pread
Chart reviews at 6 weeks and 6 months following the intervention found statistically significant differences between the numbers of advance directives on file in the experimental and control groups. Six weeks following the intervention, 15 of 87 patients in the experimental group and two of 89 patients in the control group had advance directives on file ($z=3.39; P=.0003$). Six months following the intervention, 20 advance directives were on file in the experimental group, and three were on file in the control group ($z=3.84; P<.001$ (Figure 2).

It is often difficult, using a posttest-only design, to determine whether differences between groups occurred before or after an intervention. When advance directives dated before the intervention were removed, statistically significant differences ($z=4.17; P<.001$) remained between the experimental ($\chi^2=0.207$) and control ($\chi^2=0.011$) groups (Table). Two patients in the experimental group ($\chi^2=0.023$) and two patients in the control group ($\chi^2=0.023$) had advance directives on file dated prior to the study. This was not statistically significant ($z=1.02; P=.154$).

Comparisons between completion rates at 6 weeks and 6 months following the study help to identify the lag time necessary for some patients to complete and file directives. Sachs et al. found that many patients reported put off completing advance directives. The chart review at 6 months yielded an increase in advance directives on file in the experimental group, from 15 patients (17%) to 20 patients (23%). Between chart reviews at 6 weeks and 6 months, a much smaller increase in advance directives on file was found in the control group, from two patients (2%) to three patients (3%).

PATIENT, NURSE, AND PHYSICIAN SURVEYS

Nineteen (22%) of 87 patients in the experimental group returned surveys from the follow-up mailing. Seven (78%) of nine nurses and eight (44%) of 18 physicians returned preintervention surveys on the importance of the study’s purpose; all nine nurses and 13 (72%) of 18 physicians returned postintervention surveys on satisfaction with procedures.

Preintervention Surveys

Five (71%) of seven nurses and six (75%) of eight physicians reported that it was important or very important for very ill or incapacitated patients to choose the medical treatments they receive. Five (71%) of seven nurses and six (75%) of eight physicians reported that it was important or very important to have written documentation of patients’ wishes. One (14%) of seven nurses and two (25%) of eight physicians responding to the preintervention survey reported that they had an advance directive.

Postintervention Surveys

When asked how practical the patient-physician discussion is as a method for assisting patients in completing
advance directives, eight (89%) of nine nurses and 12 (92%) of 13 physicians thought discussions were practical or very practical. Twelve (92%) of 13 physicians reported that the discussions they had with their patients took neither too much nor too little time. At the completion of the postintervention survey, two (22%) of nine nurses and seven (54%) of 13 physicians reported having advance directives, but it is not clear whether there was a true increase because preintervention and postintervention data were not available for all nurses and physicians.

Of the 19 patients who returned the mailed survey, 16 (85%) reported that they were satisfied or very satisfied with their talk with their physicians. Seventeen (89%) reported that the talk was helpful or very helpful in deciding whether to complete an advance directive. Eighteen (95%) of 19 patients reported that their physicians' explanations were clear or very clear and that the talk took neither too much nor too little time.

EXAMINATION OF ADVANCE DIRECTIVES COMPLETED BY PATIENTS IN THE EXPERIMENTAL GROUP

Of the 20 directives on file in the experimental group after intervention, 17 (85%) used the Wichita Advance Directives form. We examined how these forms had been completed to ascertain what sections were preferred by patients and to identify whether improvements could be made in the format of the document.

Four (24%) of the 17 patients completed every section of the form and had every section properly signed and witnessed. Five other patients (29%) chose to complete only one section, either the living will or the health care power of attorney, and had it properly signed or witnessed. Three patients (18%) completed several parts of the documents but had only one part properly signed or witnessed. Five patients (29%) completed one or more parts of the documents but had no parts properly signed or witnessed. In sum, 12 patients (71%) completing the new advance directive form did so in a manner that was legally binding for at least one part of the document. However, five (29%) of the directives were not properly witnessed so as to be legally binding.

COSTS

Materials for the intervention cost approximately $220. Eighteen of 87 patients in the experimental group completed an advance directive dated after the intervention. Accordingly, the direct cost per completed advance directive was about $12. This estimate, however, includes neither training time for nurses and physicians nor physician time spent conducting the intervention.

COMMENT

The results of this study suggest that an intervention consisting of a discussion about advance directives, preaddressed and stamped materials, and mailed reminders substantially increases patient completion of advance directives. A chart review at 6 weeks following the intervention discovered a large and statistically significant difference between experimental and control groups. A chart review 6 months after the intervention showed greater effects, with 33% more directives on file in the experimental group. Only one new directive was filed in the control group between chart reviews at 6 weeks and 6 months following the intervention, which indicates that the standard method of encouraging use of advance directives in the clinic (hanging out forms) had little or no effect. In a secondary finding, patients, physicians, and nurses reported that advance directives are important and that the intervention procedures were satisfactory, helpful, and practical.

As also found in a recent, large-scale study,5 some patients improperly completed their directives. The importance of this finding depends on how the document is ultimately used. Relatively few end-of-life decisions are made in court. Any written evidence of a patient's treatment preferences might be better than none and may provide guidance when families and health care providers try to determine patients' wishes. The document may not be legally binding and yet may aid in the informal decision making that often occurs at the end of life. To reduce the incidence of improperly completed forms, it may be necessary to simplify the forms or provide more assistance to patients.

We were not able to measure some effects of the intervention. For example, some patients may have completed advance directives and not filed them in their medical records. The intervention may also have sparked discussions between patients and their family members. This intervention encouraged a modicum of patient-physician communication about advance directives. Indeed, the intervention may have been the first exposure some participants (both patients and resident physicians) had to end-of-life decision making. As suggested by the "stages of change" theory of behavior acquisition,12 several such exposures may be required to prompt
patients to move from contemplation to documentation of treatment preferences.

The benefits of intervention may outweigh the costs. The $12 cost per completed directive (excluding training time and physician time) is indeed modest considering that it costs approximately $1600 a day to keep a patient in the intensive care unit of a large medical center.1

This study had several methodological limitations. First, as with most interventions implemented by multiple agents, different levels of implementation occurred. Conversations ranged from 3 minutes to 40 minutes in length, and one physician admitted afterward that he had skipped some conversations entirely. Second, we were not able to ascertain how many people used the original forms and how many used mailed materials. Third, attrition from the experimental group due to anxiety over giving consent may have introduced a systematic bias between groups, a bias not detectable by analyses of demographic characteristics. Fourth, the study was conducted in a teaching clinic at a medical center. Future research will help determine whether similar effects can be achieved in private practices or managed care settings. Finally, and most important, this study only examines a system for encouraging completion of directives. The effects of a directive on self-determination must be evaluated later in the treatment process, when the directive controls physician and family in determining treatments after the patient becomes incapacitated.

Twenty patients in the experimental group had advance directives on file at the clinic 6 months following the intervention. Why did these patients and not others choose to complete and file directives? Were they older, sicker, or in some other way more predisposed to act? We do know that physicians spent approximately the same amount of time conducting discussions with patients who completed an advance directive as they did with those who did not. Unfortunately, the number of patients completing advance directives was too small to statistically analyze whether age, gender, ethnicity, health status, educational level, or marital status correlated with advance directive completion. Larger experimental studies are better able to definitively address these questions. The present study may be viewed as one part of a research and development continuum centered on patient self-determination.

Recent studies have failed to demonstrate that advance directives directly control end-of-life decision making.23,24 Their effects seem to be limited to influencing the choice of surrogate decision maker.2 It is not clear to what extent the surrogates express patients' wishes rather than their own preferences.25 Pilot studies should be performed to further analyze the functions of advance directives and their effectiveness.

If some forms of directives prove to be effective, comprehensive interventions would be necessary to bring about their community-wide use. Until there is widespread support for advance directives by health care professionals, however, use of advance directives will likely remain restricted.

Advocacy at local, state, and federal levels could effect changes in broader policies and practices related to patient self-determination. At the federal level, health care reform could require the development and use of effective advance directives. Funds could be provided for further developing guidelines and technologies for palliative (comfort) care. More teeth could be put into federal legislation regarding patient self-determination; hospitals could be required to keep data on the number of persons possessing advance directives; and other health care agencies could be required to provide materials to patients. Unfortunately, it is likely that measures to enhance patient self-determination will remain only partially implemented as long as the PSDA and subsequent legislation remain unfunded mandates.

Medicine is changing the context of death; the patient self-determination movement is a response to that change. Medical ethicist Daniel Callahan26(p47) suggested that changes in technology and the role of medicine in alleviating pain and suffering have created "longer lives and worse health, longer illness and slower deaths, and longer aging and increased dementia." The prospect of a painful, drawn-out, burdensome death spurred development of laws and forms to facilitate documentation and implementation of end-of-life treatment preferences. The PSDA mandated patient education about advance directives. Large-scale prospective studies attempt to discover ways in which forms and protocols such as advance directives can be used to enforce patient choices and achieve patient self-determination. Studies such as the present one explore the paths by which effective directives may be disseminated to many people. Widespread adoption of treatment directives may enable more people to attain a more peaceful death,26 different from the sudden and painful passing of their ancestors and better than the drawn-out and often painful deaths of their peers.

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