Advance Directives Among Patients In A House Call Program

Mel P. Daly, M.B., B.Ch., B.A.O., D.C.H., and Jeffery Sobal, Ph.D., M.P.H.

Abstract: ***Background:*** **Advance medical directives (the living will and the durable power of attorney) provide a means for competent persons to influence treatment decisions in the event of serious illness and loss of competence. Advance directives are currently underused. We examined the awareness and number of advance directives among elderly homebound patients.**

Methods: **In a house call program for 120 elderly patients, a standardized telephone interview was conducted with 116 patients or their caregivers. They were asked whether they had a will, a living will, or had assigned a durable power of attorney. Those without advance directives were asked whether they knew what each directive was. Demographic and medical data were assessed by interview and chart review.**

Results: **More than 60 percent of the patients knew about the durable power of attorney, and more than one-half had assigned a durable power of attorney. About one-third knew about living wills, but only 5 percent had one. One-third of the patients had a will.**

Conclusions: **Advance directives are important mechanisms whereby patients can extend autonomy over the circumstances of dying. Physicians and patients should consider and discuss the issues that surround treatment in the event of terminal illness or permanent unconsciousness. (J Am Board Fam Pract 1992; 5:11-15.)**

Advance directives are mechanisms for establishing patients' preferences for medical treatment in the event of their inability to make treatment decisions.[1-3] These advance directives are important for ensuring that a patient's own desires will be followed if he or she becomes incompetent. Thus, family members and health care professionals are provided with a mechanism to make decisions that best represent the now incompetent person's wishes.

Two main types of advance directives are the living will and the durable power of attorney. A living will is a legal document that sets forth a person's wish not to receive life-prolonging medical treatment in the event that he or she becomes incompetent and has a terminal condition. The District of Columbia and more than 40 states have statutes for some type of living will, which vary somewhat among states. In many states, such as Maryland, a living will becomes a valid document only when the declarant becomes incapable of making decisions. In addition, 2 physicians must examine the patient and certify that the patient has a terminal condition and that death will occur even if "life-sustaining" treatment is instituted.

The durable power of attorney is a more flexible document in which a person gives written authorization for someone to act as that person's agent when that person becomes incapacitated or incompetent. More than 30 states have laws allowing a health care power of attorney. The durable power of attorney is frequently used to specify medical care procedures, including specifications that life-prolonging treatments are not used if the person becomes incompetent. The Federal Patient Self-Determination Act, which took effect in 1991, requires federally supported medical centers to inform patients of their rights to refuse treatment and to record the patient's decision in the medical record. This legislation will enhance the use of advance directives in hospitals and nursing homes, but it will not apply to outpatients.

The Department of Family Medicine at the University of Maryland School of Medicine has provided a house call program for frail, home-

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From the Division of Geriatrics, Department of Family Medicine, University of Maryland School of Medicine, Baltimore, and the Division of Nutritional Sciences, Cornell University, Ithaca, NY. Address reprints to Mel P. Daly, M.B., B.Ch., Division of Geriatrics, Department of Family Medicine, 405 W. Redwood Street, 1st Floor, Baltimore, MD 21201.

bound elderly patients since 1981.[4] There are 120 active patients who are visited on a routine basis every 3 to 4 months. Two physicians, both with added training and qualifications in geriatric medicine, are the primary medical providers for these patients. The present study examined the rate and patterns of advance directives in the form of the living will and the durable power of attorney among patients in the Department of Family Medicine Physician House Call Program.

Methods

All active patients in the Department of Family Medicine Physician House Call Program were interviewed by telephone using a standardized interview format. Demographic and diagnostic information was obtained from the patients' charts, and missing chart information was explored in the interview. Specifically, patients were asked whether they had a will, living will, and durable power of attorney. If they did not have one, they were asked whether they knew what each one was. Demographic data requested included sex, age, religion, mental status, annual income, and living arrangement; medical information that was assessed included diagnoses, functional status, and primary physician. The Duke University Older American Resources and Services (OARS) instrument was used as a measure of functional status.[5] This instrument assesses seven activities of daily living (ADLs) and seven instrumental activities of daily living (IADLs). These instruments are scored on a 2 to 0 ranking for each ADL or IADL assessed: a score of 2 represents independence in completion of the activity, while a score of 0 reflects full dependence. Data from the questionnaires were analyzed with a statistical package using chi-square as a measure of statistical significance at a P value of 0.05.[6]

Results

The study sample was composed of 116 of the total 120 patients. Fifty-one (44 percent) patients responded to the interviews themselves while the remainder of responses were from caregivers. More than one-fourth of the patients (27 percent) lived alone, 21 percent lived with a spouse, and 21 percent lived with an adult child. Two-thirds of the patients were women, and the mean age of all patients was 78 ± 14 years. Mean income for the majority of patients was < $10,000 (82 percent), while 59 percent of caregivers had a mean annual income > $10,000. The patients' religious preferences were Protestant (74 percent), Catholic (16 percent), other (8 percent), and Jewish (2 percent). Most were widowed (55 percent), while a smaller portion of the sample was married (23 percent), single (16 percent), or divorced or separated (5 percent). The most frequent diagnosis among these patients was hypertension (82 patients), followed by stroke (29), dementia of all types (25), hypertension (32), arthritides (17), diabetes mellitus (10), and parkinsonism (7). The mean total ADL score was 7.04 ± 5.23, with the higher ADL scores occurring in patients with predominantly psychiatric (either organic or functional) disorders. The mean total IADL score was 4.08 ± 3.96, which was significantly lower than the ADL scores and reflects significant impairment in community independence. Two physicians provided medical care for these patients, 1 cared for 58 percent and the 2nd physician for the remainder.

One-third of the patients had a will (33 percent). Older patients (age > 75 years) were more likely to have a will than their younger counterparts ($P < 0.03$). Few patients (5 percent) had a living will, and there were no significant demographic or medical differences between those who did and did not have a living will. By contrast, a much higher proportion of the patients had a durable power of attorney (53 percent). Patients who had a durable power of attorney were significantly more likely to have and know about living wills than those who did not have a durable power of attorney ($P = 0.06$). Women were more likely to have neither a durable power of attorney nor a will ($P < 0.03$). Protestant patients were also more likely to have neither a durable power of attorney nor a will ($P < 0.02$).

Patients living with an adult child or with someone other than an immediate family member were less likely to know about living wills ($P < 0.004$). Furthermore, these patients were less likely to have a will or a durable power of attorney ($P < 0.01$). No demographic or disease variables were significantly related to having a durable power of attorney among patients with a caregiver. One-third (35 percent) of the caregivers and only 28 percent of the patients knew about living wills; however 60 percent of caregivers and 63 percent of patients knew about durable power

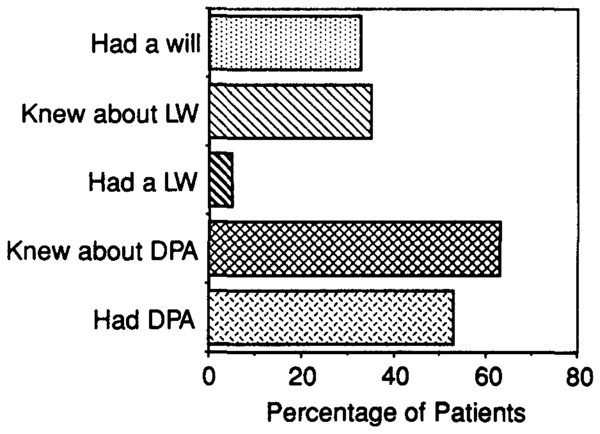

Figure 1. Percentage of patients knowing about and having advance directives.
LW = living will; DPA = durable power of attorney.

of attorney. A higher percentage of patients and caregivers knew about a living will and a durable power of attorney than had them (Figure 1). There were no demographic patterns or disease variables associated with knowledge about living wills and durable power of attorney, except that those who knew about advance directives were more likely to have them ($P < 0.01$).

Discussion

Advance directives are mechanisms whereby persons can exercise their right to make their own health care decisions if they become incompetent. In Maryland, the living will statute is limited by the requirement that the patient must have a terminal condition and death must be imminent. The durable power of attorney statute in Maryland allows for flexibility, in that the advance directive can be structured to reflect a patient's specific preferences for life-sustaining interventions. This agreement offers the advantage of decision making based on an intimate knowledge of the patient's wishes. There is some evidence, however, that proxies may not act in line with the patient's wishes or even their best interests.[7]

In many instances, physicians and family avoid discussions about these issues despite evidence that most patients welcome the opportunity to discuss their preferences about cardiopulmonary resuscitation (CPR).[8,9] A 1985 survey of elderly outpatients reported that few patients (7 percent) have a good understanding of what CPR means, yet most (87 percent) thought that discussions about CPR should take place routinely.[10] That these patients had not initiated a discussion about CPR or other advance directives with their physicians suggests that the physician must take the initiative to begin the dialogue.[10]

It is evident that advance directives are underused, perhaps because few people plan for possible inability to make medical decisions because of mental impairment or loss of consciousness. A 1982 poll of the general population found that 8 percent have made some written expression of their health care preferences should they later become incompetent.[11] A telephone survey of a random sample of 1500 people revealed that 15 percent had completed a living will and that 56 percent had discussed their preferences about life-sustaining treatment with their families.[12] By contrast, a 1986 study of 118 patients with acquired immunodeficiency syndrome reported that two-thirds had provided advance directives for their care in the case of future mental incompetence.[13] A recent survey[2] of outpatients and members of the general public in Boston found that advance directives were desired by 93 percent of the outpatients and 89 percent of the general public. Despite this finding, fewer than 10 percent had documents specifying future care, and only 5 percent reported having had discussions with their physicians about future care. Of the perceived barriers to issuing advance directives, lack of physician initiative was among the most frequently mentioned and the disturbing nature of the topic among the least. Physicians may believe that such discussions will cause their patients anxiety, depression, or fear or compromise patient defense mechanisms.

A disadvantage of living wills is that they are inflexible compared with durable power of attorney documents, which allow caretakers to adjust to new circumstances. Patients can change their minds and fail to update advance directive documents. A further disadvantage of pursuing advance directives is that obtaining a durable power of attorney often involves legal fees. These fees can be prohibitive or threatening to many. Further, the homebound status of these patients can preclude their seeing a lawyer. Another possibility for less than universal use may be that physicians lack knowledge about advance directives. A 1988 survey found that 23 percent of Colorado physicians surveyed were not familiar with the living will, and 74 percent were not familiar with the durable power of attorney.[14] The majority of these physicians did not discuss advance directives with their patients. In spite of this lack of knowledge about advance directives, it appears that physicians recognize their importance. Of 1293 physicians surveyed in 1989, almost 80 percent were supportive of advance directives, whereas fewer than 2 percent expressed negative attitudes toward such documents.[15] They claimed that the benefits of using advance directives included improved communication and trust, easier and more confident treatment decision making, less stress and guilt, and the promotion of patient autonomy.

In our study, more than 50 percent of patients had durable power of attorney documents. This rate is higher than has been previously reported.[11,12] The high rate may reflect the practice and beliefs of the physician providers who have additional training and certification in geriatric medicine and have an elderly patients practice. It seems that even frail elderly homebound patients can be encouraged to embrace the use of durable power of attorney for health care if the idea is presented by physicians. On the other hand, this high rate simply may reflect the frailty of these homebound patients. On average, these patients were moderately impaired in their abilities to perform ADLs and moderately to severely impaired in IADLs. Their ability to survive in the community is partly due to the willingness and ability of their caregivers to provide for them. In this group of patients, issues of proxy decision making about person, property, and health frequently occur.

Strategies can be implemented to increase the use of advance directives. Physicians and patients have to be made more knowledgeable about the living will and the durable power of attorney. This knowledge can be reinforced through regular physician and patient discussions. Specific recommendations can then be made, including identification of a family member or other caregiver as a proxy decision maker, provision of relevant literature, and suggestions about legal advice. Advance directives can then be established and copies made available in the medical record. The effectiveness of written advance directives is limited by inattention to them. A prospective study[3] of nursing home patients with advance directives found that in 24 of 96 acute events, the care provided was not consistent with previously expressed patient wishes. More aggressive care than had been requested by patients was provided in six cases. Eighteen events were handled less aggressively than requested. The authors cautioned against decision making for care that places priority on considerations other than the patient's autonomy.

It is possible that in our study the high percentage of knowledge about durable power of attorney was due to the caregivers imputing answers for patients. The 2 physicians providing care for these patients, however, have been enthusiastic about the use of the durable power of attorney, which could have resulted in a higher level of awareness among their patients and caregivers. It is notable that more than 80 percent of those house call patients who knew about the living will did not have one, whereas less than 20 percent of those who knew about the durable power of attorney did not have one. The low proportion of patients having a living will may reflect physician, patient, and caregiver concerns about the ambiguities and vague terms that plague the living will document language in Maryland. A living will can be invoked only after the attending physician has determined that death is imminent regardless of whether "life-sustaining" procedures are used.[16]

This study has several limitations. Patients and caregivers were asked only whether they knew about or had a will, living will, or durable power of attorney for health care. The data are descriptive and report rates that are subject to respondent recall bias. Respondents were not asked about their attitudes or experiences with advance directives or the factors influencing their decisions to obtain a durable power of attorney. Future studies using larger and more diverse samples and standardized interventions are needed to address these and other important questions about advance directives in health care. The sample size was small and restricted to a group of frail elderly patients who had physicians that promoted advance directives. Although these data are not generalizable to the entire elderly population, they are applicable to a burgeoning group of frail homebound elderly patients. More than 95 percent of persons in the US aged more than 65 years and 80 percent aged more than 85 years live at home. In 1987, 5.6 million noninstitutionalized persons (approximately 20 percent of those aged 65 years and older) had at least one ADL or IADL difficulty.[17]

The consensus in the medical literature is that patients are willing to discuss advance directives with their physicians and that physicians think that such discussions are valuable. We believe that decisions to initiate or discontinue treatment are medical decisions that should be made only after adequate consideration of the patient's wishes. Physicians should be responsible for initiating a discussion about the patient's wishes. This study reports that a high percentage of frail elderly patients are willing to encompass the concept of advance medical directives with the support of knowledgeable physicians. There is no substitute for ongoing empathic communication among health care providers, patients, and their families.

References

1. Lazaroff AE, Orr WF. Living wills and other advance directives. Clin Geriatr Med 1986; 2:521-34.
2. Emanuel LL, Barry MJ, Stoeckle JD, Ettelson LM, Emanuel EJ. Advance directives for medical care – A case for greater use. N Engl J Med 1991; 324:889-95.
3. Danis M, Southerland LI, Garrett JM, Smith JL, Hielema F, Pickard G, et al. A prospective study of advance directives for life-sustaining care. N Engl J Med 1991; 324:882-8.
4. Page AE, Walker-Bartnick L, Taler GA, Snow DA, Wertheimer DS, Al-Ibrahim MS. A program to teach house calls for the elderly to fourth-year medical students. J Med Educ 1988; 63:51-8.
5. Multidisciplinary functional assessment. The OARS methodology. 2nd edition. Durham: North Carolina Center for the Study of Aging and Human Development, Duke University, 1978.
6. Norusis MJ. SPSS/PC+ for the IBM PC/XT/AT. Chicago: SPSS, 1986.
7. Warren JW, Sobal J, Tenney JH, Hoopes JM, Damron D, Levenson S, et al. Informed consent by proxy. An issue in research with elderly patients. N Engl J Med 1986; 315:1124-8.
8. Bedell SE, Dalbanco TL. Choices about cardiopulmonary resuscitation in the hospital. When do physicians talk with patients? N Engl J Med 1984; 310:1089-93.
9. Lo B, McLeod GA, Saika G. Patient attitudes to discussing life-sustaining treatment. Arch Intern Med 1986; 146:1613-5.
10. Shmerling RH, Bedell SE, Lilienfeld A, Delbanco TL. Discussing cardiopulmonary resuscitation: a study of elderly outpatients. J Gen Intern Med 1988; 3:317-21.
11. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. Making health care decisions: the ethical and legal implications of informed consent in the patient-practitioner relationship. Vol 2. Washington, DC: Government Printing Office, 1982:217.
12. Physician and public attitudes on health care issues. Chicago, IL: American Medical Association, 1989:113.
13. Steinbrook R, Lo B, Moulton J, Saika G, Hollander H, Volberding PA. Preferences of homosexual men with AIDS for life-sustaining treatment. N Engl J Med 1986; 314:457-60.
14. Somerville J. Survey finds support among Colorado M.D.s for euthanasia. Am Med News, July 1, 1988: 17.
15. Davidson KW, Hackler C, Caradine DR, McCord RS. Physicians' attitudes on advanced directives. JAMA 1989; 262:2415-9.
16. Hoffman DE. Planning for medical decision making: living wills and durable powers of attorney. Md Med J 1989; 38:154-8.
17. National Medical Expenditure Survey. Functional status of the noninstitutionalized elderly: estimates of ADL and IADL difficulties. Research findings. Rockville, Maryland: National Center for Health Services Research, 1990; DHHS Publication No. (PHS) 90-346.