Advance directives: from the perspective of the patient and the physician

Sarah Coate Johnson MD

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American physicians and patients share some common ground in their perspectives on advance directives. The majority in both groups strongly endorse the use of these documents. Both groups believe it is the physician's responsibility to initiate the discussion about advance directives. However, a gap between the two perspectives can be defined. In end-of-life decision making, physicians balance the ethical principle of patient autonomy with other principles such as appropriate withholding of care in the setting of futility. Patients' preferences for end-of-life care are most influenced by expected outcomes. Physicians tend to be selective in their indications for initiating a discussion about advance directives, according to clinical factors. In contrast, most patients want to discuss advance directives with their physician under all circumstances.

INTRODUCTION

The 1990 United States Supreme Court decision in the case of Nancy Cruzan stated that life-sustaining treatment could not be withdrawn from an incompetent person without 'clear and convincing evidence' of agreement with the person's prior wishes[1]. This widely publicized case galvanized the American public to the importance of advance directives. Since the Supreme Court decision, advance directives have been advocated in the USA widely by the legal community, ethicists, physicians, and patients[2,3]. Emanuel found that 89% of the American public desire them[2]. However, only about 10% of Americans have prepared advance directives. Even when an incompetent patient has made an advance directive, it may not affect actual end-of-life decision making. In a prospective study of the impact of advance directives on whether a seriously ill hospitalized patient underwent cardio-pulmonary resuscitation (CPR) Teno *et al.* found no significant association between the existence of a written advance directive and decisions about resuscitation[4].

Federal laws have been passed in the USA to try to increase the use of advance directives. The Patient Self-Determination Act of 1991 required all health care institutions receiving federal funds to ask patients upon admission whether they have an advance directive. However, several writers suggest that advance directives are a clinical issue, not an administrative one. They suggest that advance directives should be addressed within the context of the individual patient–physician relationship. They note that planning for end-of-life care may be improved by sequential discussions between the patient and the physician, before the crisis of hospital admission[6–8]. What does the medical literature tell us about the perspectives of the patient and the physician on the content, discussion, and application of advance directives?

THE PATIENT'S PERSPECTIVE

Emanuel *et al.* found that advance directives were desired by 93% of outpatients. Young and healthy subgroups expressed as much interest in planning as those older than 65 years and those in fair or poor health. These researchers also found that patient preferences for life-sustaining treatment could not be predicted by their demographic characteristics, state of health, self-perceived quality of life, or personal experience of life-sustaining technology such as intensive care[2].

Patients' preferences for life-sustaining treatments are clearly influenced by the expected outcomes of the treatments. Danis *et al.* found that nursing home patients were most willing to undergo life-sustaining treatments during critical illnesses in which a return to their usual state of health was expected. They were least willing to have life-sustaining measures when a state of permanent unconsciousness was the expected outcome[5]. Also, patients' preferences frequently change after they are better informed about the

Department of Internal Medicine, University of Kansas School of Medicine-Wichita, 1010 N Kansas, Wichita, Kansas 67214-3199, USA

probabilities of health outcomes. Murphy *et al.* interviewed elderly patients regarding their preferences for CPR after a cardiac arrest before and after telling them about probabilities for survival. Approximately half of the patients who initially requested CPR refused it after learning the probabilities[9].

Patients' treatment preferences are fairly stable over time[10–12]. Danis *et al.* found no change in the preferences of 85% of American Medicare beneficiaries over a 2-year interval[12].

The majority of American inpatients and outpatients want to discuss advance directives with their physicians[8,13–18]. Individual patient preferences for the discussion cannot be predicted by their demographic characteristics. Most people believe the discussion should occur at an early age, when they are healthy[8,13–18]. Although patients believe the discussion should be conducted in the outpatient setting, they also want the matter to be discussed when they go into hospital[8]; and they expect the physician to initiate the discussion[8,14,15].

THE PHYSICIAN'S PERSPECTIVE

The general view among physicians is that advance directives enhance patient-physician communication, protect patients' rights and help provide for easier and more confident end-of-life treatment decision making[3,19].

Several researchers have investigated how physicians integrate patients' advance directives into end-of-life decision making. Fried *et al.* have suggested that end-of-life decision making can be conceptualized as a spectrum along which the wishes of the patient compete with other concerns[20]. At one end of the spectrum, the physician honours the wishes of the patient; at the other, he or she does not. For example, Fried *et al.* presented a scenario to physicians in which a patient requested a lethal injection. While nearly all would decline to administer a lethal injection, most physicians would accede to a terminally ill patient's request not to be intubated in the face of progressive respiratory failure. Factors which physicians value most in making end-of-life decisions include patient preferences, their own judgment regarding the utility of treatment, degree of patient suffering, and the patient's functional ability, age, and long term prognosis[21–23]. Several researchers have found that physicians are influenced by the diagnosis, separate from functional ability and prognosis, and are less likely to recommend resuscitation of patients with AIDS, cancer, IV drug abuse, alcoholism, and Alzheimer's disease[21,24,25] than for those with congestive heart failure.

What do physicians think about discussion of advance directives? About four in five believe it is their responsibility to initiate the discussion[14,23]. In contrast to patients' uniform desire to discuss advance directives with their physicians, physicians tend to initiate the discussion only when there are specific clinical factors. Reilly *et al.* found that patients' age greater than 75 years, critical illness, and the patients' desire to discuss end-of-life care were the most powerful factors prompting the discussion[8]. Several writers have found that patients with AIDS, metastatic cancer, late Alzheimer's disease, and terminal illness are most likely to have a discussion initiated by their physician[23,26]. Also, the physician was more likely to initiate a discussion when he or she believed the patient should not be resuscitated. Reilly found that 90% of physicians believed end-of-life issues should be discussed when they judged the patient should not be resuscitated, while 61% of physicians felt a discussion should occur when the physician believed that resuscitation was appropriate[8]. Sugarman *et al.* found that three physician attributes were predictive of a greater likelihood of initiating advance directive discussions[26]. These included younger age, female sex, and having a practice population with a large proportion of terminally ill patients.

In spite of physicians' public endorsement of advance directives, and their acceptance of responsibility for initiating the discussion about advance directives, the discussion rarely occurs. Morrison *et al.* found that the physicians they surveyed had discussed advance directives with fewer than 10% of their patients in the previous month[27]. When patients are surveyed, only about 5% of medical outpatients, 5.8% of geriatric outpatients and 3.7% HIV positive patients have had discussed advance directives with their physicians[26].

The gap between physicians' professed endorsement of advance directives and their actual practice has led some researchers to look at barriers to physician–patient communication. One of the greatest, according to Morrison *et al.*, is physicians' assumption that advance directives are only important for terminal or elderly patients; another is lack of knowledge about advance directives[27]. Physicians also admit to being 'uncomfortable' discussing resuscitation with patients[18] and fearful of upsetting patients[15]. Some physicians believe the discussion is unnecessary because they believe they already know patients' wishes[28].

Physicians and patients share some common ground in their perspectives on advance directives. The majority in both groups strongly endorse the use of these documents. Both groups believe it is the physician's responsibility to initiate the discussion. However, a gap between the two perspectives can be defined. In end-of-life decision making, physicians balance the ethical principle of patient autonomy with other principles such as appropriate withholding of care in the setting of futility. Physicians tend to be selective in their indications for initiating a discussion about advance directives based on clinical factors. In contrast, most patients want to discuss advance directives with their physician under all circumstances.

Three promising areas for future research are suggested by the gap between the perspectives of patients and

physicians. First, more studies should be done to evaluate physician office based and hospital based interventions designed to increase the use of advance directives. Two recently published randomized trials have shown that physician office based interventions are modestly effective[29,30]. Second, educational programmes for both practising physicians and physicians in training need to be developed in which effective strategies are communicated for initiating and conducting the discussion about advance directives. A small uncontrolled study has shown that up to 90% of geriatric patients completed advance directives after their physicians received this type of education[31]. Third, further work needs to be done in clarifying how to tell patients about the probable outcomes from use of life-sustaining treatments.

The ultimate goal of a written advance directive is to achieve agreement between the patient's well-informed wishes and his or her actual end-of-life care[8]. Research efforts in these three areas with concomitant changes in patient–physician communication and decisions will bring us closer to achieving this goal.

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