

# Patients' and families' receptivity to discussions about future healthcare

## *Decisions and advance directives*

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Advance directives (ADs) are an important but often neglected issue in healthcare. By preparing an AD, patients can still participate in their medical decisions even if they are incapacitated, thus sparing family members this difficult task. The goals of this study were to determine whether patients were open to being approached about ADs, to educate patients, and to promote awareness about end-of-life healthcare decisions. Over the course of a 7-week study period, 123 patients were approached in a personal interview about their knowledge of ADs while being seen at the Valley Cancer Pain Treatment Center in Scottsdale, Arizona. At the onset of the study, 28 of 123 patients had ADs. This study prompted an additional 37 patients (30%) to prepare an AD so that 65 patients (53%) had an AD at the conclusion of the study. A follow-up survey revealed that patients were comforted by having these issues addressed in a physician's office.

These results emphasize that physicians can affect end-of-life care by approaching patients about ADs. Physicians should have discussions about ADs with all patients, especially those who suffer chronic illnesses. Incorporating ADs into routine primary care comprehensive visits as a part of overall healthcare planning should be considered.

**E**ven though death and dying are inevitable, end-of-life healthcare decisions are a difficult, but necessary, topic of conversation. Fewer than 10%–15% of Americans have prepared an advance directive (AD).<sup>1</sup> Another study revealed that fewer than 12% of terminally ill hospitalized patients had evidence of an AD.<sup>2</sup> A recent study showed only 3% of terminal patients who received cardiopulmonary resuscitation (CPR) had a living will at the time of admission.<sup>3</sup> Only 27% of cancer patients admitted to the intensive care unit had an AD.<sup>4</sup> (Since politicians, the courts, and the media turned the full glare of their attention to the Terri Schiavo case, those numbers may be changing.)

ADs are documents in which individuals express their future healthcare decisions, giving instructions about what they want done—or not done—if they cannot speak for themselves. AD documents are not complicated. They can be short, simple statements expressing values and choices. By preparing an AD, patients can still participate in their medical decisions even if they are incapacitated, thus sparing family members this difficult task. It is possible to state these medical decisions in either an AD or a living will. Both are generally written docu-

### KEY POINTS

Advance directives (ADs) are an important but neglected issue in healthcare. Fewer than 15% of Americans have prepared an AD.

The goal of this study was to determine whether patients were open to discussing ADs.

In a survey, some patients believed ADs are only for the sick or the old.

Physicians and their staff can play a key role in initiating discussion of ADs and educating patients as early as possible in the course of their care.

Patients are receptive to and appreciative of these discussions. The study prompted 30% of patients to prepare an AD.

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ments; usually, ADs are more concise. Executing an AD shouldn't be a finished product but rather a dynamic process that can change depending on circumstances. Ideally, ADs need updating and reaffirmation.<sup>5</sup> The best plan is one that changes over time, as treatment options change.<sup>6</sup> Formulating an AD should begin long before the end of life is imminent and should be revisited often. But that rarely happens.<sup>5</sup>

End-of-life healthcare decisions are a highly charged emotional sub-

ject, as the Schiavo case amply illustrated. Nonetheless, it's important for physicians to take the initiative in advising, educating, and encouraging patients to create ADs. Physicians should generate discussions about ADs with all patients, especially those who suffer chronic illnesses. Many physicians feel apprehensive about discussing ADs because they don't want to increase their patients' fear of death. Other physician barriers to discussing end-of-life issues include discomfort about discussing death

with patients, a belief that discussing death can undermine hope, and a lack of time.<sup>7</sup> This discussion can be very overwhelming for both the physician and patient. Unfortunately, the subject is often broached with patients and families at the same time they are confronting a poor prognosis and family crisis—not the best time to make such important decisions.

The goal of this study was to determine whether patients were open to being approached about AD discussions during a maintenance clinic

I, \_\_\_\_\_ want everyone who cares for me to know what health care I want, when I cannot let others know what I want.

**Section 1:**  
 I want my doctor to try treatments that may get me back to an acceptable quality of life. However, if my quality of life becomes unacceptable to me and there is no hope that I will return to an acceptable quality of life, I direct that treatments (including food or water by tube or intravenously) be withdrawn. A quality of life that is unacceptable to me means (check all that apply):

- Unconscious (chronic coma or persistent vegetative state)
- Unable to communicate my needs
- Unable to recognize family or friends
- Total or near dependence on others
- Pain that cannot be controlled without sedation or confusion
- Other \_\_\_\_\_

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**Section 2: (You may leave this section blank)**  
 There are some procedures that **I do not want if it is foreseen that they will NOT bring me back to a quality of life that I deem acceptable** as per section 1.

- Cardiopulmonary resuscitation (CPR)
- Ventilation (breathing machine)
- Feeding tube
- Dialysis
- Other \_\_\_\_\_

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**Section 3: (You may leave this section blank)**  
 There are some procedures that **I do not want under any circumstances:**

- Cardiopulmonary resuscitation (CPR)
- Ventilation (breathing machine)
- Feeding tube
- Dialysis
- Other \_\_\_\_\_

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**Section 4:**  
 When I am near death, it is important to me that \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

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(Such as hospice care, place of death, funeral arrangements, cremation or burial preferences, additional end-of-life healthcare instructions/wishes, organ donation, etc.)

FIGURE 1 Healthcare directive

visit. Patients seen at the Valley Cancer Pain Treatment Center have both inactive and active malignancies. This study focused on the education and awareness of ADs because they have a shorter length and better clarity than do living wills. Patients were encouraged to talk about their end-of-life healthcare decisions with their family, close friends, and physicians. They were also encouraged to make future healthcare decisions, so that if they became unable to communicate, their ADs would guide appropriate medical decision-making.

**Methods**

Over the course of a 7-week study (June-August 2004) at Valley Cancer Pain Treatment Center in Scottsdale, Arizona, 123 consecutive patients were questioned and assessed in a personal interview regarding their knowledge of ADs.

During a routine clinic visit, verbal consent was obtained and patients were given a booklet of information and pertinent forms. The booklet included two blank AD forms (one for the patient and one for a family member) and instructions for completing the form. The booklet used was created by Health Care Decisions ([www.hcdecisions.org](http://www.hcdecisions.org)). It is available in English, Spanish, and Chinese. Only the English version was used during this study. The AD form was double-sided. One side had the healthcare directive (Figure 1). This included four sections where patients could state what “unacceptable quality of life” meant to them, list procedures they

did not want under any circumstances, and their near-death wishes such as hospice care and place of death. The other side assigned a healthcare (medical) power of attorney with mental health authority (Figure 2), allowing the named person to make medical decisions for them if they become unconscious or unable to make medical decisions for themselves for any reason.

During the initial presentation, the purpose of the study and the benefit of making an AD were explained to each patient. Patients were given a chance to ask questions; if needed, they were assisted in preparing their AD. After the form was completed, it was notarized in the clinic. The patient was given the original, a copy was placed in the patient’s file, and additional copies were faxed to the patient’s oncologist and referring physician. Three extra copies were given to the patient to distribute to family, friends, or other physicians.

If patients did not fill out the form on the first encounter, they were approached a second, third, or fourth time, either in the clinic or over the phone. Interviewers asked whether they had any questions they required help completing the form. Patients were encouraged to continue discussions about their future healthcare decisions with family and physicians. They were also reassured that their AD could be revised and amended by them at any time. If family members were interested, they could also fill out an AD for themselves and have it notarized in the clinic.

*Survey*

After the first patient encounters, an anonymous survey was mailed to the first 100 patients involved in the study. They were instructed to complete the survey anonymously and send it back in the provided stamped envelope. The survey discussed prior knowledge of ADs before being approached for the study, whether they already had a living will or an AD, and whether they filled out the document provided to them. It also asked them to comment on the difficulty of understanding and filling out the document and how well the information about ADs was conveyed to them.

**Results**

Of the 123 patients, 37 (30%) filled out the AD form provided and had it notarized in the clinic (Table 1). Of these 37 patients, 13 completed the form and signed it during the first encounter; 24 patients took the document home, filled it out, and returned it to the clinic. The mean age of these patients was 51 years old. Twenty-eight of the 123 patients (23%) already had their own ADs or living will in place prior to this study. The mean age of these patients was 60 years old. Of these 28 patients, 8 patients provided the clinic with a copy of their ADs. At the end of the study, 65 participants (53%) had either an AD or a living will in place.

Four (3%) of the 123 patients either refused information or declined to complete an AD. Two people (2%) didn’t give consent and two others refused to take any information home.

The mean age of these patients was 39 years old.

Fifty-four (44%) of the 123 patients took the booklet home to review but did not bring back a completed form. Fifty-three of these patients were approached again either in the clinic or by phone but did not bring back a completed form. The mean age of these patients was 55 years old.

Eleven family members of patients

**TABLE 1**

Descriptive characteristics of 123 patients approached about their knowledge of ADs

Patient type	N	Mean age	Female (%)
Patients completed AD provided	37	51	54
Patients with existing AD	28	60	50
Patients non-consented	4	39	50
Patients not completing AD	54	55	61
Total	123	55	56

AD = advance directives

It is important to choose someone to make healthcare decisions for you when you cannot. **Tell the person (agent) you choose what you would want.** The person you choose has the right to make any decision to ensure that your wishes are honored. If you **DO NOT** choose someone to make decisions for you, write **NONE** in the line for the agent's name.

I, \_\_\_\_\_, as principal, designate \_\_\_\_\_ as my agent for all matters relating to my health (including mental health) and including, without limitation, full power to give or refuse consent to all medical, surgical, hospital, and related healthcare. This power of attorney is effective on my inability to make or communicate healthcare decisions. All of my agent's actions under this power during any period when I am unable to make or communicate healthcare decisions or when there is uncertainty whether I am dead or alive have the same effect on my heirs, devisees, and personal representatives as if I were alive, competent, and acting for myself.

\_\_\_\_\_ By initialing here, I specifically consent to giving my agent the power to admit me to an inpatient or partial psychiatric hospitalization program if ordered by my physician.

\_\_\_\_\_ By initialing here, this Healthcare Directive including Mental Healthcare Power of Attorney is irrevocable if I am incapacitated.

Print agent ADDRESS and PHONE: \_\_\_\_\_

If my agent is unwilling or unable to serve or continue to serve, I hereby appoint \_\_\_\_\_ as my agent.

Print alternate agent ADDRESS and PHONE: \_\_\_\_\_

**SIGN HERE for the Healthcare (Medical) Power of Attorney and/or the Healthcare Directive forms**

Please ask one person to witness your signature who is NOT related to you or financially connected to you or your estate.

Signature \_\_\_\_\_ Date \_\_\_\_\_

The above named person is personally known to me, and I believe him/her to be of sound mind and to have completed this document voluntarily. I am at least 18 years old, not related to him/her by blood, marriage or adoption, and not an agent named in this document. I am not to my knowledge a beneficiary of his/her will or any codicil, and I have no claim against his/her estate. I am not directly involved in his/her healthcare.

Witness \_\_\_\_\_ Date \_\_\_\_\_

This document may be notarized instead of witnessed.

On this \_\_\_\_\_ day of \_\_\_\_\_, in the year of \_\_\_\_\_, personally appeared before me the person signing, known by me to be the person who completed this document, and acknowledged it as his/her free act and deed. IN WITNESS THEREOF, I have set my hand and affixed my official seal in the Country of \_\_\_\_\_, State of \_\_\_\_\_, on the date written above.

Notary Public \_\_\_\_\_

**FIGURE 2** Healthcare (medical) power of attorney with mental health authority

who completed an AD in the clinic also completed an AD for themselves. None of the family members of patients with an existing AD, nor family members of those who did not return the AD to the clinic, completed an AD for themselves.

### Survey

Thirty-three patients responded to the mailed survey (33% response rate). Seventy-seven percent of these patients stated they had heard of ADs prior to being approached in the study, whereas 36% of the survey respondents had a living will or AD in place. Fifty-two percent found that the AD form was easy to complete, 41% moderately easy, and 7% found it difficult. Survey respondents indicated that it was beneficial to have the information presented in a relaxed, informa-

tive, and professional manner.

### Discussion

Since the majority of the patients had been diagnosed with cancer, death is a well-known, but not always a comfortable, topic. After explaining to skeptical patients that everyone should have an AD, regardless of their current health, they realized they were not being targeted because they were cancer patients; many then became more comfortable with the topic. The ADs were also offered to family members in an effort to promote awareness about end-of-life healthcare decisions, which subsequently, made the patients feel more comfortable with the topic.

These types of decisions are not easy but, ideally, should be faced at some point in life. Many patients

were comfortable freely discussing their ideas of end-of-life healthcare. These findings were similar to other studies in which patients expressed that they do want to talk about ADs; they want their physicians to initiate these discussions during healthy periods, rather than during an illness or hospital admission.<sup>8,9</sup> Upon inquiry, quite a few patients had been intending to fill out an AD but had not yet done so. Some patients had discussed ADs in cancer support groups.

One study showed that patients were unsure how to obtain ADs and hadn't completed one because none had been made available to them.<sup>10</sup> The present study made ADs available to patients, in addition to prompting and motivating them to complete them now rather than wait until it was too late. Patients seemed to prefer

ADs to living wills because of clarity and shorter length. Three patients, who already had living wills, filled out an AD during the study because they found it to be a more precise description of their wishes. In addition, they found it easier to distribute to their family members and physicians since it was shorter and more concise.

The results of this study are evidence of the importance of ADs and the necessity of ADs being offered by physicians. This study examined how patients and their families responded to discussions in the physician's office about ADs and the options associated with death and dying. Many patients who wanted an AD were given

the chance to fill one out and have all their questions answered. Several patients hadn't filled out an AD because they found them confusing and appreciated the assistance provided. At the completion of the study, 53% of patients involved had completed an AD or living will. These results show that physician-initiated discussions play a role in prompting patients to complete an AD. In addition, this information was put into their medical record and dispersed to their oncologist or referring physician. One study showed that half of all people with ADs had secured their only copy in a safe deposit box.<sup>10</sup> Additional copies should be made available to the patient's phy-

sician, family members, and designated surrogate decision-makers.

Of the patients approached, 98% openly discussed ADs and the goals of end-of-life healthcare decisions. Another study showed that most people are open to discussions regarding decision making about resuscitation and want to express their wishes for end-of-life care.<sup>6</sup> Of particular interest, the younger patients were less likely to fill out an AD in the present study. Other studies looking at perceived barriers to patients executing ADs showed that people believed ADs were relevant only for the sick or the old.<sup>4,11</sup> Age should not be a factor in this decision, as one does not know what medical problems may arise.

## The value of educating patients about advance directives

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Ideally, discussions about advance directives should take place when a person is well, and the documents should be revised regularly. These simple acts would reduce the burden of decision-making in a health crisis and facilitate communication among family members and professional caregivers. They might even spare the kind of agony played out in excruciating detail by the media in recent months as Terri Schiavo's family fought over the right to withdraw her feeding tube. A timely conversation about goals of care and restrictions on use of technologies in a non-confrontational setting can help increase public awareness of the complexities of end-of-life care. We already have a model for such settings: "health fairs" that offer cholesterol and blood pressure screening.

In real life, these discussions are often precipitated by a crisis, awk-

wardly handled by inexperienced doctors, and misguidedly linked to immediate plans of care. Decisions to intubate or cardiovert, to remove respirators or feeding tubes in hospital settings, are undoubtedly shaped by emotion, time pressures, ambivalence, and grief. These are threatening conversations with immediate repercussions on life or death; they can result in long-term psychological consequences for those who survive—family members, loved ones, as well as the professionals involved. The spouse who agrees to discontinue life support needs to come to terms, not just with her husband's death, but also with her changed role as a widow. Well-meaning doctors in search of decisions often fail to provide appropriate support to family members; instead, these physicians rush them to find action-oriented solutions.

In this study by Stearns et al, patients at the Valley Cancer Pain Treat-

ment Center were given a booklet of information and an advance directive form. They were encouraged and coached to complete it. In 7 weeks, the number of patients with completed forms almost doubled. This study confirms that we can do more to increase awareness in the general public and among patients seen in outpatient settings for non-urgent visits. Outreach efforts at public libraries, community forums, and informational campaigns may increase the yield even further. What remains to be seen, is whether these efforts targeting healthy people or patients with chronic but stable disease, will ultimately translate into a reduced burden of suffering for patients and families at times of critical and pressured decision-making.

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A large proportion of patients, no matter what their health status or age group, desire medical care planning.<sup>11</sup>

A study by Emanuel et al also showed that patients' favorable attitudes of planning for medical care were due to the patient education component of the discussions.<sup>11</sup> Similar to the current study, the Emanuel et al study also involved providing patients with an extensive AD form outlining different treatment options and clinical situations, which was discussed during a structured personal interview.

The current study had some limitations. The study population only included patients who were seen at the Valley Cancer Pain Treatment Center. The fact that they had already been diagnosed with cancer could bias the study results. Because of their disease, such people may be more willing to be approached about AD issues.

Physicians can play a key role in broaching the subject of end-of-life healthcare decisions with their patients. Presentation of ADs should be given adequate time and forethought. Within the time constraints of a busy practice, it can be challenging to find time to initiate the process of advance care planning, educate the patient and family regarding end-of-life issues, and fully listen to the concerns of the patient.<sup>5</sup> This task need not be addressed by the physician alone but can be accomplished in conjunction with appropriate office staff. Designating staff personnel to discuss, educate, and procure ADs allows the physician to answer pertinent and pressing questions. This can allow the patient and his or her family more time to make these difficult decisions without pressure. Therefore, they can make more thoughtful decisions regarding their wishes for end-of-life care. One

study looked at favorable receptivity of the do-not-resuscitate (DNR) discussion scenarios.<sup>12</sup> It showed that the least favorably rated scenario for discussing DNR orders involved a physician or staff member who had no prior contact with the patient. Specifically, the patient was much less likely to agree to DNR orders when the discussion was conducted with a physician who had no established relationship with the patient.

Physicians should provide this education, awareness, and encouragement as early as possible in patient care. The Schiavo case further stresses the need for ADs or living wills. Had Terri Schiavo prepared a living will, her family would not have been faced with the years of difficult and controversial decisions. Even though she was mentally disabled, she would have been able to guide her own care. Legislation regarding end-of-life healthcare decisions should be addressed, and a national database should be established for easy access to these documents by all healthcare providers.

The debate over keeping Terri Schiavo alive highlights how poorly death is handled in the US. Hopefully, the public attention focused on this case will increase awareness and discussions regarding this topic. The results of this study indicate that patients are receptive to and appreciative of discussions about ADs with their physicians and staff. It is crucial for physicians, in their practice, to initiate and incorporate these discussions about ADs and living wills.

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