

Communication through advance directives

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Summary. There are two kinds of justifications for advance directives. The first is that they extend patient autonomy into the future, allowing individuals to control or at least influence their care after they have lost the capacity to make decisions. The second is that they help physicians and family members make emotionally stressful decisions in difficult circumstances. Whether directives are written or unwritten is of secondary importance. The primary concern is that they are based on an adequate understanding of medical options. Two cases illustrate the relative importance of these features of advance directives.

Key words: Advance directive, living will, self-determination, informed directive.

Advance directives are recognized legally in the United States and are gaining increased attention in Europe. Through such documents, individuals attempt to influence their future medical care after they have lost the ability to participate in treatment decisions. There are two broad ways of influencing one's future care. First, one can leave information or instructions about how one wishes to be treated. Documents that communicate treatment wishes are often called "living wills" in the United States. Second, one can designate another individual to make treatment decisions for oneself. It is possible in many American states to authorize a specific person as one's legal representative in matters of health care, conferring substantial power to make almost any decision that one would be unable to make for oneself. In this paper I will focus on instruction directives, or "living wills."

There are at least two kinds of justifications for respecting advance directives. The most obvious is that they can expand the scope of patients' control or influence over difficult treatment decisions. They record choices that individuals make for a possible future in which they are unable to make decisions for themselves. All too often, when difficult decisions must be made at the end of life, patients are unconscious and so unable to express a preference about further treatment. If they have expressed their preferences in advance in a sufficiently clear manner (and documented in the record), however, they can continue to guide the choices of those who care for them.

Controlling to some extent the way we die is important to many individuals because death is, as the cliché

goes, the "final chapter" in the story of our lives. We may view our lives as having a narrative structure requiring a certain kind of ending. To the extent that we have tried to live a life according to certain basic values and commitments, we may want to die in a way that honors those values and is a fitting ending to the life-story we have created. Not everybody feels this way, and it is certainly possible to romanticize such a concern. It would be wrong to expect everyone to plan the ending of their lives or to belittle those who do not share such concerns. Putting oneself in the hands of others is a perfectly legitimate approach to the end of life. Forcing people to have a certain approach to death is as coercive as denying them a choice in the matter. Respect for individual self-determination requires both that we leave people free to die without a prior plan, and that we honor their plans if they choose to make them.

Individual self-determination is a central value in Western societies. It is not the only value, to be sure. We should not be free to act in ways that harm others or undermine social cooperation. We must contribute our fair share to common endeavors. There is general agreement, however, that mature individuals should be able to make choices about their own lives for themselves, as long as they understand the consequences of their actions, even if those choices are harmful to themselves or unwise from the perspective of others. Self-determination in this sense is widely regarded as a central element of human dignity. Advance directives extend the reach of self-determination, and that is one reason for honoring them. It is also a reason for making them, to some extent, legally binding.

There is a second powerful reason for creating and honoring advance directives. When patients are incapacitated at the end of life, difficult decisions must be made about life and death. Since patients are unable to choose for themselves, others must determine the course of treatment for them. In the U.S. we typically turn to the family, who may then be faced with agonizing choices. Often they must choose between allowing the patient to die, and prolonging suffering without hope of recovery. This is a very heavy burden to bear. It should be easier to make such a choice if the family has some assurance of what the patient would want. Knowledge that the patient has approved the choice in advance should also make family members more confident of their decision and relieve to some extent any guilt they might feel about letting the

patient die earlier than absolutely necessary. A further concern may be that financial resources not be squandered in prolonging a life of very low quality. Families may worry especially about taking the cost of treatment into account, appearing to place an economic value on the patient's life. European citizens with generous health care benefits or well-insured American families may still be concerned not to waste social resources on marginally beneficial care. Decisions to forgo costly treatment that has little benefit at the end of life should be easier if the patient has specifically declined it. Here, then, is a second kind of reason to encourage and respect advance directives: they ease the burden on family members and on health care professionals when difficult decisions must be made.

There is empirical evidence for these assumptions about the benefits of advance directives. In one survey of physicians who had experience with such documents in their practices, agreement with the following statements was strongly positive:

1. Family members reach agreement on treatment options with greater assurance when the patient has an advance directive (86% agreement)
2. Family members experience less guilt about not "doing everything" if the patient has an advance directive (89%)
3. Advance directives facilitate physician-family agreement on treatment options (91%)
4. My attitude toward advance directives has become more positive as a result of my experience with them (83%)¹

It is for this second set of reasons that I personally have completed an advance medical directive. I am less concerned about retaining control than about easing my family's burden of choice. It is not that I want to choose for them. I want instead to comfort them and assure them they have made the right choice. Physicians may want to recommend advance directives to their patients for these reasons, regardless of concern about preserving individual autonomy and regardless of the legal status of the documents.

The two kinds of reasons we have for creating and for respecting advance directives, that they extend patients' self-determination and that they help families make difficult decisions, normally reinforce one another. Tensions can arise, however, if we focus exclusively on one justification or the other. If we think of advance directives primarily as extensions of individual autonomy, we tend to see them as instruments to control future actions of others. Seeing them as instruments of control may emphasize their similarities to legal documents. We may be concerned that they were properly executed, that they conform to recognized standards, that they are properly recorded, and so on. Then, if they do not match up, we may ignore them as "not legal." To approach them as legal orders from patient to doctor can divert our attention from their second important purpose, to help others make ex-

ceedingly difficult decisions for the patient. If we think of them as primarily documents of assistance, then attention is shifted away from formal requirements and toward their utility in producing the best outcome for all. Of course certain minimal legal requirements must be met. The patient must have given the instructions free of duress, for example, and it must be legally possible for the instructions to be followed. Broad concern for legal details should be balanced, however, by concern to help struggling families arrive at decisions that are best for the patient and that provide comfort for the survivors.

A balanced approach to these two purposes of advance directives is usually, but not always, possible. Sometimes we are forced to choose between the two values of following the patient's choice and helping the family to reach a decision that is best for all. The following cases illustrate the difficulties of such a choice as well as some other important issues surrounding advance directives.

Case One

A.B. was a 35 year-old female who presented to her local physician with tiredness in September. She eventually had laparotomy and splenectomy, at which time a diagnosis of lymphoma was derived. She developed a post-operative fever and was felt to have a staphylococcus infection. The sepsis prolonged the time of recovery from surgery and delayed referral for therapy for her lymphoma. Eventually she was evaluated in December but delayed her admission for chemotherapy until January because of personal problems. Though the delay may have decreased somewhat her chances for a cure of the lymphoma, there was still a good possibility of recovery.

A.B. was admitted in January for her first cycle of chemotherapy. Approximately 24 hours after the initiation of her chemotherapy she was found to have respiratory distress. She was noted to be febrile to 39 C. She was confused, and her blood gases indicated acidosis. A thoracentesis was performed on the ward. She continued to deteriorate, however, and was transferred to the intensive care unit. The possible reasons for her deterioration were felt to be sepsis, tumor lysis syndrome, or respiratory distress due to increased fluids.

When the patient was transferred to the intensive care unit, her family was notified and told that mechanical ventilation would be necessary for her survival. They arrived with an advance directive signed by the patient. They refused permission to place the patient on mechanical ventilation, because A.B. had stated at Christmas time that she never wanted to be intubated for any reason.

Case Two

E.F. was a 72 year-old male with a recurrence of throat cancer. He had been treated with full course radiation 18 months earlier, having refused surgery for the recurrence. He had been successfully treated surgically for a tongue cancer 5 years before the current admission, but the surgery was very traumatic physically and emotionally. A tracheostomy had been required after the tongue resection. The tracheostomy was removed within 2 weeks after surgery; but the patient said it was the worst thing he had ever endured, and he would never do it again.

¹ Davidson KW, et al (1989) Physicians' attitudes on advance directives. *Journal of the American Medical Association* 262: 2415-2419.

He presented in pain and with moderate respiratory distress. Breathing produced a loud noise, indicating a serious airway obstruction. On examination, a large tumor recurrence was seen in the hypopharynx, involving the larynx; and the surgeon recommended an immediate tracheostomy. E.F. refused, however, saying he would rather die than have another tracheostomy. He was admitted to hospice care and was managed for a short while at his home. The difficulty breathing increased slowly but steadily. He continued to adamantly refuse tracheostomy.

He was admitted to the hospital with severe difficulty breathing and in moderate pain. He was placed on a subcutaneous morphine infusion at 4 mg/hr, which rapidly controlled his pain. He remained lucid and in severe respiratory distress, but he continued to refuse tracheostomy. His wife did not want to see him suffering, but she honored his wishes not to have a tracheostomy, which would have immediately alleviated his airway distress. His two daughters by a previous marriage, both of whom lived out of town, entered the picture just as E.F. became mentally confused and unable to respond coherently. They demanded a tracheostomy be done to relieve his incredible suffering. No written advance directive had been completed by E.F. stating a tracheostomy should not be done, and he had never informed either daughter of his wishes. His wife succumbed to the stress of the situation and became non-functional at this point, refusing to take part in any decision making. His daughters maintained that he had no idea how much and how long he would suffer by refusing a tracheostomy; and if he could respond now, he would want the procedure done.

These cases highlight several important issues with advance directives.

Informal directives. It is helpful if patients have written directives, but it should not be necessary. The important thing is that the patient's wishes be known. A direct but unwritten communication from patient to physician can be just as effective as a written document in expressing treatment preferences. It can often be more effective if it expresses a choice about a specific procedure in a specific situation. Thus the refusal by E.F. of palliative surgery is a genuine advance directive. The same values that justify honoring formal written directives also justify honoring informal unwritten directives. Though their ethical weight does not depend on being written, a prudent physician will document patients' informal directives in the medical record. Notes in the medical record serve the same function as advance directive documents: they are evidence of the patient's choices. It is important to document such choices in case there is disagreement about the proper course of treatment, as there is in both of the cases above, or to guide other physicians who may be involved in the care of the patient.

Adequate understanding. Occasionally instructions in a directive appear to be uninformed. The most common example is a blanket refusal of intubation. Very few individuals would reject intubation under every circumstance if they knew it might mean their unnecessary death. There is a popular misconception that every patient placed on a ventilator remains permanently attached to it. Television programs typically depict mechanical life support as the

end stage, usually pointless, in the treatment of a fatal condition. Rarely do they show patients recovering from an emergency condition after a short period of assisted ventilation.

The informal directive refusing intubation in Case One may well be an instance of an uninformed directive. The patient's condition is far from hopeless. If she survives the immediate crisis, she has a greater-than-equal chance of living significantly longer. It would be unusual for a patient who understood this situation to refuse temporary life support. For this reason one should be quite skeptical that the supposed directive is well informed. Unless presented with good evidence to the contrary, one should assume that the patient would disavow the directive if she were made aware of the consequences of following it. As with any refusal of life-saving treatment, it should be based on adequate understanding of the available alternatives. People should not die because they misconceive their options and, as a result, give uninformed directives.

The informal directive in Case Two refusing tracheostomy is more difficult. Unlike A.B., this patient has experienced intubation and has an extremely strong aversion to it. His directive is not naïve. He knows what it would be like, and he would rather die than undergo it again. One can respect his refusal of a tracheostomy as a life-saving procedure, yet question whether on balance it should be done for palliative reasons. His children think he could not have understood the degree of suffering his refusal would entail. On the other hand, he continued to refuse the procedure when lucid and in severe respiratory distress. The directive seems to be as well informed as it could be in such a situation.

Self-determination and the family. Whatever one thinks about the epistemic quality of the directive in Case Two, one will be moved by everyone's suffering, the family's as well as the patient's, and will want to find a solution that is best for all. Thus we are brought back to the two kinds of justifications for advance directives. If we view them primarily as instruments for extending patient autonomy, we may be inclined to weigh the patient's refusal of the procedure more heavily. If we view them primarily as instructions to assist the family to bear the burden of difficult decisions, we may focus less on the patient's directions and more on easing the family's distress. I believe that both are valid reasons for creating and for honoring a directive. When they come into conflict, a compromise is sometimes possible that does not violate the essential intention of the patient. If no compromise seems available, however, and there is little doubt about the knowledge and intentions of the patient, I believe the patient's directive should be honored. Though reasonable people of good will may disagree about these two cases, I think the patient's apparent directive should be set aside in Case One and honored in Case Two.

Communication. The tension between these two approaches to advance directives can perhaps be diminished if we stress their role as documents of communication.²

² King NMP (1996) Making sense of advance directives. Georgetown University Press, Washington, D.C.

Their purpose is to help the family and the treatment team to determine what is best and most fitting for the patient from the patient's own perspective. Each party has a role to play in this process of communication. The patient (that is, the person creating the directive) should try to become informed about issues at the end of life and know what kinds of decisions might typically need to be made. Instructions should be thoughtful and as clear as possible in a brief document. Even if standard forms are used, further guidance can be added on a separate sheet of paper. If the individual is currently diagnosed with a serious disease, such as a progressive dementia, it should be especially helpful to anticipate and address specific crises that can be expected during the course of the disease.

Physicians are in the best position to help patients understand the decisions that will be faced and the options that are typically available. This is especially true for patients who have been diagnosed with a serious condition. Physicians can review the patient's directive to be sure it is intelligible and that it accurately reflects the

patient's wishes. Quizzing the patient about specific potential treatment scenarios may be helpful in understanding general statements or instructions, for example, instructions about intubation.

In addition to reviewing it with their physicians, individuals who complete a directive should review it with family members who might need to help make medical decisions. Directives contain mostly general instructions that will have to be interpreted for the specific decisions at hand. Direct discussions about the individual's values and goals for medical care will allow family members to clarify their uncertainties about the intentions embodied in the directive and be better prepared to represent the patient's wishes.

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