

Advance Directives

We believe that God is sovereign and is able to intervene in human affairs using natural or supernatural means. We also believe we are stewards of our bodies, our health and our resources, and therefore we are responsible to God for our lifestyle and healthcare choices.

Advance directives are discussions or written statements which convey a person's wishes to his or her family and physician in the event that he or she becomes unable to discuss such matters. They may (1) explain the individual's values about health, life and death; (2) give directions to family and physician about treatment goals or the use or non-use of specific treatment modalities; or (3) designate a surrogate to make decisions on behalf of the individual.

As Christian physicians and dentists, we believe that advance directives can be an important part of good stewardship. We should consider prayerfully having such discussions and completing written advance directives ourselves. We should encourage our patients to do the same.

Prior to completing an advance directive, the Christian should consider prayerfully God's will for his or her life. Family, clergy and other Christian advisors may be of assistance to the believer who is uncertain about the application of biblical principles and Christian tradition to his or her particular situation. The believer should formulate his or her advance directive to assure that it clearly and accurately reflects his or her values and wishes.

After completing an advance directive, the individual should discuss its content and meaning with his or her family, surrogate, and physician. Individuals should review their advance directives periodically to assure that they accurately reflect their current values and wishes.

Clinicians should examine carefully the verbal and written wishes expressed by their patients. They should be willing to follow these wishes provided they do not conflict with the clinician's personal moral or religious values. If such a conflict exists, the clinician should discuss it with the patient and transfer care if the conflict cannot be resolved.

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Explanation

Background

Prior to the 1960's, whether a particular patient with a particular condition should be treated with a particular treatment was a decision made primarily by that patient's physician or dentist. The professional stance was paternalistic in that the clinician benevolently imposed his or her values on the subordinate patient. This was not only common practice, it was accepted by both patients and professionals as the way things were and the way they ought to be. Several things have happened in our culture which has

changed that acceptance, including: (a) the development of more treatment options, many of which are invasive, burdensome, and expensive, and some of which have less than ideal efficacy; (b) the emergence of the legal doctrine of "informed consent"; and (c) the rise of individual rights as manifested by increased emphasis on minority rights, consumer rights, patient rights, etc. One of the results of the social ferment of the 1960's is that "medical paternalism" has become a pejorative term and "patient autonomy" has become dominant. The individual patient's values now most often take precedence over the values of the individual clinician or the profession as a whole. Thus at the same time that there are more (and more difficult) decisions to be made, the ultimate authority for making those decisions has shifted from the physician or dentist to the patient. As will be discussed later, this shift has been a mixed blessing.

Patient Refusal of Therapy

During this time of transition, there was a public perception that physicians were often too aggressive in treating patients beyond the time when it was reasonable to limit treatment and accept the inevitability of death. In the 1970's, patients and families began to not only question the wisdom of prolonged aggressive treatment, they also began to challenge some treatment decisions in court. Karen Quinlan's family was the first (1976) to go to an appellate court level (New Jersey) to request the discontinuation of treatment which was felt by physicians to be necessary to sustain life. That landmark court decision to accede to such a request was the first of 50 or more handed down from appellate judges over the next 15 years which eventually established several legal precedents including: (a) competent patients have the right to refuse even life-sustaining treatment; (b) incompetent patients have the same right, and that right may be exercised by a surrogate; (c) the family is the presumptive surrogate for an incompetent patient; (d) there is no legal difference between withholding and withdrawing a treatment; (e) it is not necessary to go to court to make these decisions; (f) a physician or hospital, acting in good faith, will not be held liable for following such requests; and (g) artificially administered fluids and nutrition are treated the same under the law as any other treatment modality. Of course, everything legal is not necessarily ethical from a Christian perspective.

Advance Directives

Most of the contentious cases have involved patients who had lost their decision-making capacity because of illness or injury. Advance directives have been devised as a way for persons, while still competent, to communicate to family or physician what they would want to have done if they should become unable to make their own decisions. These directives may address treatment goals, the values underlying treatment decisions, specific treatment modalities, or who should act as surrogate decision-maker.

In 1967, Louis Kutner proposed a written document he called a Living Will in which a person could express his or her treatment wishes. His proposal attracted little attention or support until 1976 when the public discussion of Karen Quinlan caused many to desire a way to record their wishes. In 1976, California became the first state to enact a law (The Natural Death Act) recognizing the validity of an advance directive. Subsequently nearly all jurisdictions have passed such enabling legislation. Many states have prescribed wording, others merely give legal recognition to the concept. The completion of Living Wills has been encouraged by many medical and lay organizations, including The Society for the Right to Die (now called Concern for Dying).

Living Wills are documents giving instructions about goals of treatment. Most are written in a negative tone, e.g., "...If I should be in an incurable or irreversible mental or physical condition with no reasonable expectation of recovery, I direct my attending physician to withhold or withdraw treatment that merely prolongs my dying..." Some include instructions about specific treatment modalities which the patient declines. Some are worded in a positive way to say what treatments the person would want to have under certain conditions. One format called the Medical Directive is designed to allow the person to choose which of 12 different treatment modalities he or she would or would not want to have in each of 4 different clinical situations.

A Values History is a detailed document through which a person can convey the information necessary to make a treatment decision. For example, a person might indicate that the ability to communicate with others (or to recognize others, or to listen to music, etc.) is more valuable to him or her than continued living.

Another form of advance directive is a proxy statement, i.e. the designation of what individual the person would trust to make medical decisions if he or she should lose decision-making capacity. The most popular form is a Durable Power of Attorney for Health Care. Such documents may or may not include specific directions for the proxy to follow. The assumption behind a proxy statement is that the person named to act as the agent knows the patient's values, goals, and/or specific treatment wishes.

The 1990 Patient Self-Determination Act was passed by Congress as an amendment to the Omnibus Budget Reconciliation Act. It requires all health facilities which accept federal funds to ask each patient on admission if he or she has an advance directive, and then to give information about advance directives to all who do not have one but would like to learn about them.

In spite of enabling legislation and popular support, only 10-15% of the adult population in the U.S. have completed an advance directive. Reasons for reluctance include denial of the need for such documents, suspicion of unnecessary "legal documents", concern that the motive behind societal encouragement of advance directives is to decrease health care costs, and suspicion that Right to Die advocates are trying to impose their values, which are often contrary to a Right to Life philosophy. In addition, some have expressed concern that signing an advance directive requesting some limitation of treatment in some circumstances may be misinterpreted as a request for no treatment at all, or that it might result in the withholding of measures needed to ensure comfort and dignity.

Secular vs Christian Perspectives

Several assumptions underlie the use of advance directives: (a) treatment decisions require valid consent, (b) not everything that can be done must be done, (c) it is prudent to anticipate loss of decision-making capacity, (d) it is helpful to provide guidance for surrogate decision-makers, (e) both verbal discussion and written documentation are helpful. These assumptions fit squarely and solidly with the secular concept of decision-making where the wishes of the autonomous individual are dominant.

When advance directives were first proposed, many Christians were opposed to them fearing that acceptance of these documents could be used by "right to die" proponents to facilitate the premature withdrawal of treatment from handicapped individuals, or even that they could lead to euthanasia. Upon further reflection, most Christians are now comfortable with these assumptions; none is in conflict with biblical teaching. However, Christians ground these assumptions in a framework also shaped by scripture. Biblical freedom (with the decision-making responsibility that flows from it) is distinctly different from the common contemporary understanding of autonomy. Autonomy today typically means both that decisions critically affecting a patient's life should be made by the patient, and that whatever decision a patient makes is right simply by virtue of the fact that the patient has made it. A Christian perspective challenges both of these claims.

First, the biblical writings do affirm that even the crucial decision for or against Christ with its definitive implications for one's eternal life is a matter of personal responsibility--not to mention important decisions that affect life in this world. However, while affirming and protecting the individual, a biblical outlook also emphasizes the significance of community, which is rarely commended in an autonomy-based approach. The best treatment refusal decisions are typically made together with one's physician, taking into account the well-being of family, friends, and others, and not merely oneself.

Second, while the biblical writings do suggest that we must allow people to refuse even life-sustaining therapy--because it is their decision to make--all such decisions are not necessarily right. Contrary to autonomy-based thinking, a biblically based decision to limit treatment, whether through a patient refusal of therapy or through an advance directive, is constrained by the addition of other assumptions not generally considered in a secular perspective. Added to the assumption of (f) the patient's freedom (properly understood) are such concerns as (g) the sanctity of life, (h) the sovereignty of God, and (i) the stewardship required regarding our bodies and our resources.

Some evangelical Christians remain fearful of advance directives feeling that they are too vague, or that they give too much authority to a surrogate or a physician who might then act differently from what the patient wants. The importance of such worries and the potential for various differences between the secular and the Christian perspectives led the Christian Medical and Dental Society to develop statements on Patient Refusal of Therapy and Advance Directives.

Abstracts

Orentlicher D. Advance medical directives. JAMA 1990; 263(17):2365-2376

The author is a physician-attorney who works with the AMA Ethics and Health Policy Council. A living will is legal a document by which a person can dictate the kinds of life support that should be used and under what conditions they should be used. They have drawbacks in that they may be ambiguous or they may not address the specific clinical situation which the patient may encounter.

A legal document to appoint a health care proxy (e.g., a durable power of attorney for health care) has the advantage over the living will in that it is more flexible, and should thus obviate the need to go to court to make a decision in an ambiguous situation. However, if family members disagree with the decision of the proxy, they may still institute a court challenge on the grounds that the proxy is not being consistent with the patient's desires.

He encourages physicians to initiate discussion of advance directives with patients and to document treatment wishes expressed by the patient in their chart. In addition, those treatment preferences should be periodically reviewed and updated.

Emanuel LL, Emanuel EJ. The medical directive: a new comprehensive advance care document. JAMA 1989; 261:3288-3293

This is a description of a "second generation living will" which allows the person to indicate which of 12 treatment modalities he or she would or would not want to have used if he or she should become incapacitated in 4 different clinical situations. The modalities listed are: cardiopulmonary resuscitation, mechanical breathing, artificial nutrition and hydration, major surgery, kidney dialysis, chemotherapy, minor surgery, invasive diagnostic testing, blood or blood products, antibiotics, and pain medications. The 4 clinical situations are: permanent unconsciousness, persistent unconsciousness with a small chance of improvement, irreversible dementia accompanied by a terminal illness, and irreversible dementia without other illness.

The authors give the reasoning behind the development of their "Medical Directive" document, and give instructions for patients as well as advice for physicians on its use.

Lambert P, McIver-Gibson J, Nathanson P. The values history: an innovation in surrogate medical decision-making. Law, Medicine & Health Care 1990; 18(3):202-212

The authors point out that advance directives are designed so that surrogates can make health care decisions for patients after they have lost their competence. Typical advance directives address the questions of who should make the decision or what decision should be made. They propose that the more important question is "what are the patient's values?". They then offer an alternative advance directive which focuses on the patient's values rather than their desires about specific treatment modalities. Their 6 page sample "Values History" contains 61 questions. However, they describe it as more than a series of questions, but a process of reflection and communication.

Grogin MA. Religious advance directives: the convergence of law, religion, medicine, and public health. Am J of Public Health 1993;83(6):899-903

Because of the deep interpersonal significance of decisions made at the end of life, it is not surprising that religion has played an important role in patient and family decisions. Religious traditions can serve as an important source of "guidance, order, purpose, understanding, meaning, solace, and hope." Specific religious concerns about death and dying have led to religious advance directives. Advance directives offer a case study of models of interaction between religious communities and secular institutions.

In this paper, a physician examines why advance directives have been developed to conform to specific religious traditions, and how this may affect health care decisions. He analyzes their strengths and weaknesses and concludes that specific religious instructions are unnecessary in written directives and may even undermine both the religious and the healthcare goals of the patient.

Jaggard, Peter. Advance Directives--The Case for Greater Patient-Physician Dialogue, in Dignity and Dying: A Christian Appraisal. Grand Rapids, Mich.: Eerdmans; and United Kingdom: Paternoster, 1996.

The author invokes a consideration of the medical-ethical dilemma which often confronts physicians whose seriously ill patients have not clearly communicated their wishes regarding treatment and have become incompetent to express them. He includes a review of the various forms of advance directives and contends that Christian physicians must recognize and act in accordance with biblical perspectives relevant to the issues resulting from the use of advance directives. Such perspectives include those which address the nature of human life and death, the compassion of Christ for those who suffer, and the biblical mandates for stewards and shepherds.

Bibliography

Bedell SE, Delbanco TL. Choices about cardiopulmonary resuscitation in the hospital: when do physicians talk to patients? N Eng J Med 1984; 310(17):1089-1093

One of the first articles to point out that a physician's opinion about a patient's desire for resuscitation correlates poorly with preferences expressed by the patient.

Peters DA. Advance medical directives: the case for the durable power of attorney for health care. J Legal Med 1987; 8:437-464

Peters provides persuasive arguments why the Durable Power of Attorney for Health care document is preferable to the Living Will.

Hamel RP. Advance directives compatible with Catholic moral principles. Health Progress April 1988:36-40,88

A description of advance directives and a discussion of their compatibility with Catholic principles.

Churchill LR. Trust, autonomy, and advance directives. Journal of Religion and Health 1989; 28(3):175-183

Trust has been largely ignored in contemporary bioethical discussions and also by the courts. The language of autonomy, privacy, and rights is useful but insufficient to speak to moral experience. This analysis of the Brophy case encourages a more central role for the concept of trust.

Lynn J. Why I do not have a living will. Law, Medicine & Health Care 1991; 19:101-104

This geriatrician expresses her concern that the effects of having a Living Will might be worse than not having one. She closes with an endorsement for the Durable Power of Attorney for Health Care document.

Vermont Ethics Network. Taking Steps to Plan for Critical Health Care Decisions. Vermont Ethics Network, 89 Main St., Waterbury, VT 05676; 1991

An excellent practical booklet in question-and-answer format giving clear information about advance directives.

McGarrick PM. Living Wills and Durable Power of Attorney: Advance Directive Legislation and Issues. Scope Note 2; National Reference Center for Bioethics Literature, Kennedy Institute of Ethics; Georgetown University, Washington DC, 1991

This 20-page review lists 1991 advance directive statutes from all 50 states, and contains an extensive annotated bibliography of government documents, court decisions, books, manuals, articles, and audiovisuals on the topic.

Short D. Should doctors support the living will? Journal of the Christian Medical Fellowship April 1992:10-12

A British professor of medicine is critical of Living Wills and encourages physicians to improve the standards of terminal care.

Schniederma LJ, Kronick R, Kaplan RM, Anderson JP, Langer RD. Effects of offering advance directives on medical treatment and costs. Ann Intern Med 1992; 117:599-606

This study of the treatment and cost of care for 204 patients found no significant difference in patient's well-being, health status, medical treatments, or medical treatment charges for patients with or without advance directives.

Hare J, Pratt C, Nelson C. Agreement between patients and their self-selected surrogates on difficult medical decisions. Arch Intern Med 1992; 152:1049-1054

This empiric study showed a high rate of discrepancy between the desires of patients and their surrogates' understanding of their desires, and is one of several such studies and opinion pieces which question the validity of "substituted judgment" in making health care decisions.

Danis M, Garrett J, Harris R, Patrick DL. Stability of choices about life-sustaining treatments. Ann Intern Med 1994; 120(7):567-573

This empiric study showed that 85% of patients who had chosen to forego life-sustaining treatments did not change their minds two years later.

Weeks WB, Kofoed LL, Wallace AE, Welch HG. Advance directives and the cost of terminal hospitalization. Archives of Internal Medicine 1994; 154:2077-2083

Contrary to the findings of Schneiderman, et al, (above) this empiric study of 336 patients who died in a university hospital found that patients without advance directives incurred hospitalization charges which were 1.6 times those of patients with advance directives.

Supplement to Hastings Center Report. Nov-Dec 1994; 24(6):S1-S36

This supplement includes 12 articles which resulted from a multi-disciplinary conference to assess the current state of knowledge about decision-making for incapacitated adults, giving special attention to the role of advance directives and aiming to establish priorities for further theoretical and empirical research. A major focus is on the question of whether the current emphasis on advance directives is correct.