Advance Directives

For Decision-Making in Health Care

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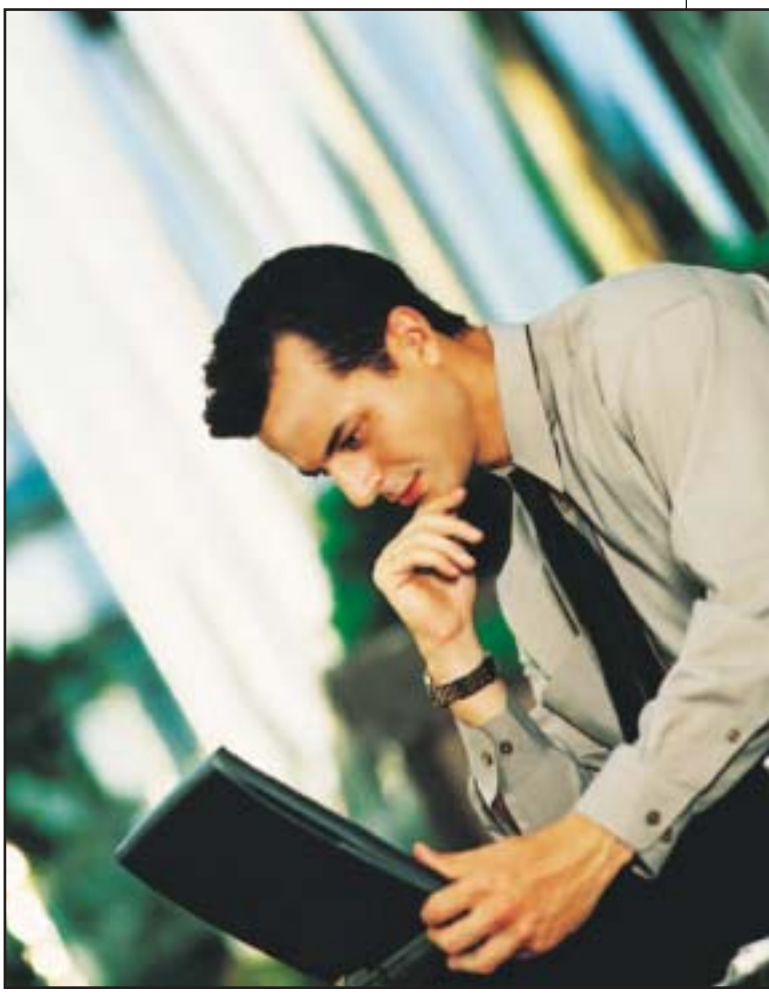
Presented at the Third Annual Practical Management of Common Medical Problems Conference, Saskatoon, Saskatchewan, November 2001.



In Western medicine there are well-accepted standards for decision-making. A broad range of treatments is typically considered and either offered to, or withheld from, patients. Treatments not offered might not be indicated, while treatments withheld might be classified as incapable of achieving the desired goal. Other reasons treatments are withheld may involve high costs, accessibility concerns, a lack of clinical data or because, on balance, they are more harmful than beneficial.

When a treatment is indicated, it usually is discussed with patients to obtain informed consent. Current standards promote patient autonomy and self-determination. Even when treatments are indicated, demonstrably beneficial and low-risk, patients have the right to either accept or refuse them.

When a patient is incompetent or unable to participate in decision-making, physicians must look elsewhere for guidance on whether or not a treatment is acceptable. In recent years, advance directives have gained acceptance as fair representations of previous autonomy. A large majority of patients, however, either do not have directives or have inadequate ones. In these circum-

stances, doctors must approach substitutes or proxies to seek consent from those who best understand the patient's wishes.

Definitions

An advance directive (also known as a health-care directive or living will) is a set of instructions, wishes or desires regarding health-care decisions, to be used as a guide in the event a person becomes incompetent. A proxy directive can simply name a substitute; that is, a person who will make decisions on behalf of the directive's author.

Other directives are meant to serve as decision-making guides (instruction directives) and can vary from being highly specific and detailed to very general or brief. Combination directives are also common. In these, the patient documents specific or general requests, but also names a proxy who can be asked by health-care providers to offer real-time interpretations should the need arise.

Although usually employed in circumstances of permanent incapacity, directives also can be used during periods of temporary incapacity, such as those resulting from delirium and head trauma. It is important to note that directives are only employed in the event an individual becomes incapacitated; they have no relevance or meaning while a patient is still able to make competent decisions.

The major advantage of proxy appointment over an instructional directive is that proxies are not required to foretell the future.

Historical Relevance

Living wills were originally promoted by groups advocating the right to die. These groups viewed the medical establishment with great distrust, and saw the vast majority of care near the end of life as technologically driven, undesirable and inappropriate. Early directives often included vague or unhelpful language, such as "extraordinary treatments" or "heroic measures."

Since the late1980s, advance directives have become part of mainstream medicine. Most nursing homes and long-term care facilities now encourage all residents to fill out directives. Many associations for chronic illnesses promote living wills and, in the United States, the Patient Self-Determination Act even requires public hospitals to ask all patients on admission whether they have such documents.

Although these documents have gained legal recognition in most Canadian provinces, rules vary from one jurisdiction to another. Generally, any adult person with the capacity to make health-care decisions can make a directive. This makes good ethical sense, given our understanding of the consent process and the right to self-determination.

Logically, mature minors also should be entitled to have one, but legislation varies on this point. Unless prevented by statute, Canadian common law permits minors to make health-care decisions, so long as they fully appreciate the nature and conse-

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Summary

Advance Directives For Decision-Making in Health Care

- An advance directive (also known as a living will) is a set of instructions, wishes or desires regarding health-care decisions, to be used as a guide in the event a person becomes incompetent.
- A proxy directive can simply name a substitute; that is, a person who will make decisions on behalf of the directive's author.
- Although these documents have gained legal recognition in most Canadian provinces, rules vary from one jurisdiction to another.
- The main goal of advance-care planning is to ensure that health-care decisions accurately reflect a patient's preferences, even when the patient is unable to participate in decision-making.

quences of the proposed treatment. With respect to advance directives, health-care providers are advised to contact their own regional health administrators and local colleges of physicians and surgeons to determine current practices.

Theoretical Basis For Directives

The main goal of advance-care planning is to ensure that health-care decisions accurately reflect a patient's preferences, even when the patient is unable to participate in decision-making. The creation of an advance directive does not necessarily accomplish this goal; advance-care planning is a process, requiring discussions among all concerned over a period of time.

Consent is now an accepted treatment norm. It is grounded in the ethical principles of respect for autonomy and self-determination. Advance directives help to ensure the norm of consent is preserved and respected, even after a patient is no longer able to discuss treatment options with his/her caregivers. With the increasing recognition of individualism, free choice and autonomous self-determination, a broad societal consensus has emerged. This consensus gives competent patients, or their surrogates, the legal and ethical authority to refuse or accept not only life-sustaining therapies, but therapies of any kind.

Obviously, an incompetent patient cannot make autonomous decisions, and there is no

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purely logical justification for extending this rights-based claim from the competent state to the incompetent. Support for advance directives, therefore, resides more properly within a respect-for-persons ethic.

Proxy Decision-Making

Any competent and willing adult can act as a proxy, but again, the rules vary from province to province. The process to be followed when more than one proxy is named, or when the named proxy is unavailable or unwilling to make a decision, is governed by legislation in most places.

The intent of advance directives — that is, the extension of patient autonomy — is best served if the proxy knows and understands the patient well and if health-care matters have been previously discussed over a period of time. The major advantage of proxy appointment over an instructional directive is that proxies are not required to foretell the future. They can make decisions at specific times using specific facts, and proceed in a manner consistent with the attitudes and general life plans of the individual involved.

Proxies should be encouraged to act according to the wishes previously expressed by the person requiring treatment. When these wishes are unknown, proxies must decide according to what they perceive to be the patient's best interests. Health-care providers need to realize disclosure is just as important for proxies as it is for competent patients.

As with any health-care decision, including those made in advance directives, a proxy decision may be challenged. There might be evidence suggesting the proxy misunderstands the situation or is incapable of making a competent decision. All too frequently, the proxy is an absent family member who arrives at the time

of crisis. As a result, guilt-laden decisions and questionable motives may arise. The health-care team has a responsibility to provide the proxy with all pertinent information so the patient's best interests can be truly served.

Limits To Advance Directives

Directives ought to be challenged when there is good cause to question the author's true intent or accuracy of prediction regarding the current situation. Since serious life-and-death decisions are often at stake, health-care providers need to act cautiously. They should err on the side of sustaining life, especially when incapacity is thought to be temporary. If the proposed therapy is routine and the condition commonly curable, caregivers are justified in questioning the rationality of any expressed prior refusal by the patient.

Advance directives should be challenged when their enactment would injure others or when they seriously conflict with the equal rights of others. Similarly, directives should not be followed blindly when doing so might damage the community, or when illegal acts are requested. The right to decide is not an absolute right, but rather a conditional right, enacted within the context of friends, family, caregivers and community.

Drafting Advance Directives

Most experts agree advance-care planning is a process, not an event. Consequently, it cannot be successfully completed during one clinical encounter or during the course of one family meeting. More specifically, advance-care planning involves attitudinal changes, and these changes might take place over months or years. Thus, although well-intentioned, many printed living will forms tend to foster neglect of the necessary and lengthy discussion process by reducing life-and-death decision-making to a mindless fill-in-the-blank exercise.

Physicians, particularly family physicians, are

Practice Pointers

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well-suited to assist patients with drafting directives. While personal choices, no matter how idiosyncratic, must be respected, it remains useful for patients to make their choices based on realistic medical knowledge. Physicians can describe, for example, what it means to be placed on a ventilator, to be fed artificially or to be dialyzed on a permanent basis. They can have several examples of directives available for patients to peruse. Family doctors tend to know their patients better and over a longer period of time than do their specialist colleagues. This can help in determining and presenting the factual knowledge most essential and relevant for any given patient.

When life expectancy is limited by serious illness, the discussion grows more explicit. Care providers should ask whether the patient has important things yet to accomplish, and whether provisions in the advance directive might further these ends. Patients should be encouraged to discuss their plans while they are still in reasonable health, and physicians should offer to help clarify medical wishes as laid out in advance directives. Directives should be updated at least twice yearly, and all such discussions should be carefully documented in the patient's chart.

Conclusion

It is possible the emphasis we place on naming preferences about specific technologies and interventions is misdirected. Our main interest should be to continue to reflect on the goals of care. This can be achieved by discussing how advance directives can facilitate patient education, meaningful dialogue and negotiation of health-care choices.

Ideally, advance directives ought to increase the odds that people will live and die the way they want, within the limits of the clinical situation and society's moral and legal boundaries. Research is needed to investigate the best methods for educating people about the appropriate use of advance directives and to develop ways of evaluating the effects of this education. Like any health-care intervention, the preparation of an advance directive must remain optional. Choosing not to choose must remain a valid choice. CME

Suggested Readings

1. Singer PA, Robertson G, Roy DJ: Bioethics for Clinicians 6: Advance Care Planning. Can Med Assoc J 1996; 155(12):1689-92.
2. Lazar NM, Greiner GG, Robertson G, et al: Bioethics for Clinicians 5: Substitute decision-making. Can Med Assoc J 1996; 155(10):1435-37.
3. Hebert PC: *Doing Right: A Practical Guide to Ethics for Medical Trainees and Physicians.* Oxford, Toronto, 1996, pp. 30-5.

Helpful Web Sites

1. Public Legal Education Association of Saskatchewan: Health Care Directives.
   www.plea.org/freepubs/hcd/hcdpg1.htm#living_wills
2. Provincial Health Ethics Network (Alberta): Personal Directives.
   www.phen.ab.ca/perdir/main.html
3. University of Toronto Joint Centre for Bioethics: Living Wills.
   www.utoronto.ca/jcb
4. Living wills registry (Canada).
   www.sentex.net/~lwr/detail.html
5. Molloy W: Let Me Decide Program.
   www.newgrangepress.com/LMD.html
6. *www.mindspring.com/~scottr/will.html*
7. *http://palliative.info/Links/AdvDir.htm*
8. Alzheimer Society of Canada: End-of-life planning.
   www.alzheimer.ca/english/care/ethics-endoflife.htm