Beyond Living Wills

by Mark Tonelli

Living wills are ineffective, primarily because they are too ambiguous to guide medical decision making and because the problem they were designed to address no longer exists to any significant degree. Attempts to reformulate instructive directives and make them more clinically relevant are unlikely to succeed. Responsibility for avoiding inappropriate care at the end of life lies not with patients, but with health care practitioners.

About twenty years ago, public awareness that human life, devoid of quality or meaning, could be prolonged through technological means reached a level that demanded action. Stories like that of Karen Ann Quinlan invoked a response that forced both the medical profession and government to take action to help alleviate perceived injustices in the way some patients were being managed at the end of life.

Coinciding with our ability technologically to maintain the life of persons who were by most accounts as good as dead was the rise of patient autonomy as a prevailing principle guiding physician-patient interactions. Again, legal decisions brought this classic philosophical concept of personhood to the public's attention. Courts found that the right to self-determination not only allowed competent individuals to refuse life-sustaining medical therapies, but that this right extended via "standards of logic, morality and medicine" to the incompetent patient (Eichner 1980). Clearly, however, incompetent persons cannot directly exercise such a right. Mechanisms were required to allow such patients either to stipulate preferences in anticipation of future inability to do so, or for others to exercise the right to self-determination for them. At first, advance directives for medical treatment appear to fulfill this goal. Instructive directives such as living wills allow people to express preferences regarding the provision of specific medical interventions, while proxy directives such as durable powers of attorney for health care, allow them to designate surrogate decision makers.

Advance directives, judging from surveys of both patients and physicians, are popular. They have a statutory basis in all fifty states, and the federal government has encouraged their use by enacting the Patient Self-Determination Act. Studies have been undertaken to find efficient ways to encourage patients and the public to write these documents. Into the overwhelming consensus that instructive directives are beneficial, however, has crept a troubling fact. Instructive directives, like the living will, do not work.

The Failure of Living Wills

Multiple studies have demonstrated that living wills have no apparent impact on end-of-life care.[1] I have argued elsewhere that this lack of effect should be neither unexpected nor disheartening (Tonelli 1996). Living wills are ambiguous legal documents people often completed without discussion with health care professionals. As a result, living wills sometimes are left to be interpreted by physicians, often those who have no previous knowledge of the patient. Due to practical and philosophical limitation, no instructive directive can be taken at face value; each must be validated. But attempts to validate living wills demand that independent evidence in support of them be found. This is the same process physicians already should use in attempting to reach decisions about the care of their incompetent patients. The process involves discussions with surrogates, as designated

by a proxy directive, and family members and loved ones regarding prior preferences of the patient, as well as evaluations of the patient's current interests. Physicians should not mistakenly assume that the legal preference for written documents means living wills are ethically superior to other types of evidence regarding prior preferences. In the process of validating instructive directives, we render the documents themselves irrelevant to medical decision making. Studies have failed to find any difference between the care of patients with or without living wills. This may simply indicate that physicians and families continue to address the complex and difficult questions regarding the care of incompetent patients in a thoughtful, thorough, and individual manner, rather than taking short-cuts provided by the presence of a living will.

This critique of living wills can be misinterpreted by some to be a reactionary call to return to the days (if ever there were such days) when authoritarian physicians fought to maintain life at any cost, even over the protests of patients and families. On the contrary, the near irrelevance of living wills should serve as a wake-up call. Those who maintain that these documents provide protection of individual autonomy and prevent unwanted use of invasive technology prior to death must realize that their work is far from done. By ignoring the fact that living wills have no demonstrable effect on end-of-life care, we increase the likelihood that such care will remain inconsistent and often inappropriate. If living wills, as currently formulated, are not the solution to the perceived inadequacies of contemporary end-of-life care, then we must seek other, more effective approaches. Before doing so, however, we must clarify what inadequacies of care currently exist.

A Changing Problem

The SUPPORT study (*JAMA* 1995) seemed to reaffirm that medical care near the end of life is profoundly flawed, that such care fails to serve the interests of patients or families, and that it is marked by the overtreatment of dying patients. Subsequently, however, authors of the SUPPORT study said this interpretation was erroneous. Ninety percent of dying patients in the study, on further analysis, appeared to agree with the care they received.[2] Reasons for prevalent misconceptions about quality of death may be relatively simple. Nobody wants to die in an intensive care unit (ICU), but patients are generally willing to risk dying in the ICU for the possibility, virtually always present to some degree, that aggressive therapy may provide them the opportunity for meaningful survival. When it is clear that this opportunity has been lost, a vast majority of physicians should be, and are, comfortable withdrawing support. If we believe that death in the ICU is inherently a "bad" death, as the authors of SUPPORT initially seemed to, then closing ICUs is the simplest and most effective way to avoid such outcomes. If, however, patients are willing to risk dying a "sub-optimal" ICU death in an attempt to realize a potential benefit of prolonged or improved survival, then dying in an ICU will not be an affront to personal autonomy or to patient well being. Only when we define a "good death" independently of patient preferences, does it seem that more than ten percent of critically ill patients suffer "bad deaths."

We turn now to the small minority of patients whose care at the end of life does not appear to coincide with their wishes. For these patients, it becomes important to determine the manner in which choice and care diverge. Although living wills are promoted as tools to extend personal decision making, from a practical standpoint they encourage a particular type of choice: the refusing of medical interventions perceived to be invasive and valueless near the end of life. Some forms of these directives do provide an opportunity to request life-sustaining therapies regardless of prognosis. However, this has always been viewed by the proponents of living wills as the "default" actions physicians will take in the absence of alternative instructions. That is, instructive directives were not designed to tell doctors to take aggressive action to preserve the life of individuals. They were designed, rather, to tell doctors to cease and desist short-sighted use of technology in the service of goals not desired by patients, their families, or by society at large. Nearly all

living wills now written prohibit such behavior and attempt to prevent overtreatment. In doing so, they may cause new threats to patient autonomy.

Although it is unclear how often permanently comatose or terminally ill patients are kept alive despite previously expressed wishes or substituted judgments of family members, it seems clear to those who care for the critically ill that this happens relatively infrequently. The rise of patient autonomy and the importance of quality of life concerns has had a profound impact on the practice of medicine, independently of the presence of advance directives. Physicians often broach the subject of withholding or withdrawing before patients or surrogates raise the issue. There are subtle and not-so-subtle pressures on physicians to limit resources spent on the dying. The entire recent debate on medically futile treatments demonstrates that physicians want to be empowered to limit the use of life-sustaining technologies. In short, the goal of medicine has changed from the simple preservation of life to the prevention of untimely death, with an additional exhortation to provide a peaceful death.[3] Physicians by and large have embraced this shift in philosophy. With this shift, the likelihood that patients will be overtreated has dropped dramatically. Instead, the risk of undertreatment relative to patient wishes may now predominate.

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There is some empirical evidence that current threats to patient autonomy are likely to come in the form of under treatment. Danis (see endnote #1) recorded preferences of 175 nursing home patients regarding potential future treatments. Three-quarters of those patients were treated in accordance with those previously stated wishes, and the presence of an advance directive did not increase the likelihood of this concordance. More relevant, for those patients who were not treated in accordance with their previously expressed wishes, three-quarters received less aggressive care than they appeared to desire. If a primary goal of advance directives is to limit the use of invasive, expensive, and unwanted technologies when these treatments provide little or no benefit, this objective may be achieved without the help of living wills.

It is hard to argue that the current state of death in the United States is close to the best it can be, especially given misconceptions currently surrounding the SUPPORT study. Even acknowledging a problem, we need to be humble about our ability to solve it. Death, as Eric Cassell noted two decades ago, is likely to remain "mostly smelly and mean, preceded and followed by pain." Those in the medical community must realize that the ability to provide every individual with a good death is as limited as our ability to provide them all with a good life. With this in mind, we can begin to look at approaches and interventions more limited in scope and ambition than living wills that, nevertheless, may help avoid inappropriate or unwanted medical care near the end of life.

Potential Solutions: Improving Directives

The major practical and philosophical limitation of living wills is their ambiguity. Although patients wish to allow physicians and families significant flexibility in making future decisions on their behalf, the interpretation required for these documents, by necessity, undermines their value. By leaving the interpretation of living wills to physicians, we allow such documents to become mechanisms for limiting spending on the dying, rather than for ensuring individual autonomy (Levinsky 1996). If the goal of extending individual autonomy is to be realized, instructive directives must be unambiguous.

Providing exhaustive checklists of possible interventions will not provide this increased level of certainty. Patients still will need to know in advance the context in which those interventions might apply (Brett 1991). Unambiguous instructive directives, then, must meet at least one of two conditions: 1) either they must apply in all clinical contexts, or 2) they must describe preferences only for very specific and unambiguous clinical situations.

Examples where the first condition is met include a refusal of blood products on religious grounds, and the portable "No CPR" provided for in some states. Those who write such instructive directives must be made aware that they will, in fact, be considered valid regardless of the clinical situation. Availability and use of portable "No CPR" directives currently is in flux and varies from state to state. In addition, these documents may be considered binding only on Emergency Medical Service (EMS) personnel, and do not necessarily restrict transport to hospitals. States may limit enforcement to people who are terminally ill and may require a physician co-signature. A less ambiguous form of such a directive might simply refuse all medical treatment except for alleviation of pain, that is, a portable "Comfort Care Only" order.

Such prohibitions on care may provide some protection from invasive end-of-life treatments for terminal patients who wish to die at home. It should immediately be evident, however, that such instruments would lack appeal to the general population. With the exception of ardent religious prohibitions, refusal of specific therapies by healthy individuals regardless of clinical context seems foolhardy. Advance directives that prohibit care regardless of clinical context seem appropriate only for individuals who view their lives as no longer worth living, and who are comfortable with the risk of dying prematurely from potentially reversible conditions. It is doubtful that even many terminally ill and debilitated patients would wish to take such a risk.

If people are unlikely to want advance directives that apply in all clinical contexts, even when they are chronically ill, perhaps the answer is for them to craft documents that address only narrowly defined clinical situations. Such disease-specific instructive directives will need to anticipate future states accurately and allow people to express preferences for care very likely to be required in the course of the disease. For instance, an advance directive regarding mechanical ventilation for a patient with end-stage emphysema or amyotrophic lateral sclerosis could be framed in unambiguous terms and would probably become applicable at some point in the progression of the patient's disease. Other lethal diseases could be treated in a similar manner. I doubt, however, that such documents would prove significantly more valuable than current instructive directives.

Despite their added clarity, disease-specific advance directives will remain hobbled because actual end-of-life decisions invariably are more complex than those we can anticipate when we complete such documents. The likelihood of surviving an acute event, the burdens of proposed treatments, the development of complications, the probability of long-term survival, and the functional level we expect to achieve if we survive, all must be factored into any decision to provide or withhold a particular intervention. All these factors would need to be anticipated in formulating an unambiguous advance directive. But such added specificity not only would make completing the document more difficult, it also would limit the actual situations where the directive can be invoked. Simply put, any attempt to make instructive directives more resistant to variation in interpretation will necessarily make them less likely than ever to be applicable.

Lengthy discussions with many patients have convinced me that the vast majority of them share a relatively simple preference regarding end-of-life care: they wish to undergo any treatment that provides a significant chance to return to a quality of life that they deem acceptable, but they do not wish to be maintained with supportive measures otherwise. The trouble with translating this nearly universal desire into a meaningful written advance directive is this: decisions regarding

treatment are best made in real time, within the context of the immediate clinical situation, when the prognosis and benefits and burdens of treatments are most accurately, though still imperfectly, known. Although universal prohibitions on specific therapies regardless of clinical context and disease-specific instructive directives may let a small number of patients effectively dictate their future medical care, such less ambiguous documents fall far short of providing broad improvements in end-of-life care.

Potential Solutions: Professional Standards of Care

Advance directives cannot help avoid inappropriate care at the end of life to any significant degree. Rather, proper use of medical technology comes when medical practitioners understand and accept the medical, ethical, and social limitations of such technology. Improving care at the end of life requires that we develop professional standards of medical treatment, standards that reflect an ethical and scientific consensus (Dresser 1994). Although care of the dying as well as care of the living must be individualized, physicians and their professional organizations need to help define circumstances where curative or supportive care must give way to comfort care. The rise of autonomy over the last several decades has left the medical profession fearful of appearing to be "paternalistic" or "authoritarian," charges leveled when virtually any portion of medical decision making is said to rest with physicians. Such fears need to be overcome.

Cases where living wills are invoked today identify a class of circumstances where professional standards of care can more easily be substituted to accomplish the desired goals. When a patient is terminally ill and has no significant chance of recovering even to baseline functioning, and where medical treatment only "prolongs death," no previous expression of patient preferences prohibiting such treatment need be sought. Withholding or withdrawing medical therapy in such situations is virtually mandated. Professional codes allowing for physicians to refuse "futile" therapies represent a first step in developing standards for the care of the dying. "Futility" remains a contentious notion. Although it remains difficult to define the limits of appropriate medical therapy, some treatments in some situations clearly are inappropriate, even when life-sustaining.

Certainly proponents of advance directives will react with disdain to any suggestion that patient autonomy, even the severely weakened autonomy of an instructive directive, is anything less than the primary principle of medical decision making. As we have seen, living wills demand interpretation by physicians, leaving it to those physicians to determine when such directives apply and how they should be implemented. Living wills provide no protection from "paternalistic, authoritarian" physicians. Moreover, they do nothing to ensure that end-of-life care will be delivered in a fair and uniform manner. Only by developing professional standards of care can we help assure that the dying patient will be treated appropriately regardless of which physician they choose or are assigned in the final days of life.

Of course, guidelines for care of the dying should not prohibit any particular treatment agreed upon by a physician and a patient or his surrogates. Clinical medicine remains focused on providing benefits to individuals and must always take place within the physician-patient relationship. But I see no reason why the current proliferation and support of clinical practice guidelines for everything from asthma to zoster should not include end-of-life care. Appropriate treatment for those in a persistent vegetative state, those with profound neurologic injury, or those with progressive dementia must be considered. Technological attempts to improve prognostic accuracy in seriously ill patients have yet to exceed the skill of experienced clinicians in any relevant way. A more careful analysis of subgroups of patients may define circumstances where survival is unprecedented, and these will be ethically and socially comfortable places to begin to limit care regardless of patient preferences.[4] The current focus on living wills and attempts to salvage instructive directives only

distract us from the task at hand. So long as we refuse to admit that instructive directives can never ensure appropriate treatment of the dying, we fail to approach the problem in ways that can result in ethically and socially defensible standards of care.

Conclusion

Living wills have failed. Still, articles continue to be published demonstrating new and better methods to encourage patients to complete these documents. Such interventions cannot be considered successful. The completion of an advance directive will have no impact on one's end-of-life care.

The most direct method of ensuring appropriate and just care of the dying lies in developing professional standards of care and in educating physicians in the ethical and social bases of such standards.

Nor should we support the use of living wills simply because patients seem to like them. Promoting ineffective instructive directives is ethically analogous to prescribing a placebo. Even if we think it will make the patient feel better, withholding knowledge that the intervention is ineffectual is an affront to the very notion of autonomy used to support living wills. There also is a danger that patients will view their written advance directive as a necessary and sufficient means to ensure a good death. It is neither, but such a belief may prevent the types of discussions among patients, their loved ones and health care providers that truly will be useful in making future medical decisions. Living wills put a form ahead of a process; the process is valuable, the form is not.

The key to improving care of the dying lies not with the dying but with their caretakers. Although I believe that problems associated with current end-of-life care are exaggerated and that our collective ability to ensure a good death for all is limited, there still is room for improvement. Unambiguous instructive directives eventually may prove helpful to a small number of patients who wish to refuse specific interventions regardless of clinical context or to those who have reached a state where they wish no further medical intervention at all. But living wills never can be the populist panacea they originally were conceived to be. The most direct method of ensuring appropriate and just care of the dying lies in developing professional standards of care and in educating physicians in the ethical and social bases of such standards. Such standards must be developed with input from a broad spectrum of sources, from patients to ethicists. These standards will not transform dying into an always welcome, dignified and comfortable process, but they will do more toward these ends than living wills. They certainly cannot accomplish less.

Endnotes

1. See, for example, Danis, M., L.I. Southerland, et al. 1991. "A Progressive Study of Advance Directives for Life-Sustaining Care." *New England Journal of Medicine* 324:882-888; Schneiderman, L., R. Kronick, et al. 1992. "Effects of Offering Advance Directives on Medical Treatments and Costs." *Annals of Internal Medicine* 117: 599-606; Teno, Joan, J.Lynn, et al. 1994. "Do Formal Advance Directives Affect Resuscitation Decisions and the Use of Resources for Seriously Ill Patients?" *Journal of Clinical Ethics* 5:23-30.

2. See Kolata, G. 1997. "Living Wills Aside, the Dying Cling to Hope." *New York Times.* New York: B10(N), C(10(L) Col. 5. It is interesting that this relatively high concordance rate is buried within the text of a paper — Lynn, J., J.Teno, et al. 1997. "Perceptions by Family Members of the Dying Experience of Older and Seriously Ill Patients." *Annals of Internal Medicine* 126 (2): 97-106 — that still concludes that large numbers of patients experience "bad" deaths. This suggests that the authors have defined a "good" death independently of patient preferences.

3. See Jonsen, A.R., M. Siegler, and W.J. Winslow. 1992. Clinical Ethics. New York: McGraw Hill, and International Project of the Hastings Center. 1996. "The Goals of Medicine: Setting New Priorities." *Hastings Center Report* 26 (6): S1-S27.

4. See, for example Rubenfeld, G., and S. Crawford. 1996. "Withdrawing Life Support from Mechanically Ventilated Recipients of Bone Marrow Transplant: a Case for Evidence-Based Guidelines." *Annals of Internal Medicine* 125: 625-33. Certain criteria define groups of bone marrow transplants where survival was unprecedented.

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