HEALTH POLICY

The Need for Safeguards in Advance Care Planning

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The recent uproar about Medicare "death panels" draws attention to public and professional concerns that advance care planning might restrict access to desired life-sustaining care. The primary goal of advance care planning is to promote the autonomy of a decisionally incapacitated patient when choices about life-sustaining treatments are encountered, but the safety of this procedure has not received deserved scrutiny. Patients often do not understand their decisions or they may change their mind without changing their advance care directives. Likewise, concordance between patients' wishes and the understanding of the physicians and surrogate decision makers who need to represent these wishes is disappointingly poor. A few recent reports show encouraging outcomes from advance care planning, but most studies indicate that the procedure is ineffective in protecting patients from unwanted treatments and may even undermine autonomy by leading to choices that do not reflect patient values, goals, and preferences. Safeguards for advance care planning should be put in place, such as encouraging physicians to err on the side of preserving life when advance care directives are unclear, requiring a trained advisor to review non-emergent patient choices to limit life-sustaining treatment, training of clinicians in conducting such conversations, and structured discussion formats that first address values and goals rather than particular life-sustaining procedures. Key targets for research include: how to improve completion rates for person wanting advance care directives, especially among minorities; more effective and standardized approaches to advance care planning discussions, including how best to present prognostic information to patients; methods for training clinicians and others to assist patients in this process; and systems for assuring that directives are available and up-to-date.

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THE CASE

A vigorous, sharp-witted elderly woman with mild pneumonia, when asked late at night in the emergency department about accepting intubation if her respiratory infection worsened, gave a clear decision that she did not want to be put on a ventilator. The next morning, her primary care physician asked her the question slightly differently, accompanied by realistic prognostication: would she accept a few days of mechanical ventilation in order to get through the worst of the chest infection, understanding that she would very likely recover fully? She said, "Of course."

INTRODUCTION

The scare about Medicare "death panels" that surfaced in the debate over health care reform may not seem worth serious consideration. How could a health care regulation that simply fostered advance care planning (ACP) at an annual doctor's visit erupt into public outcry with claims that physicians might sentence unwilling seniors and disabled persons to a premature death? How could an attempt to promote patient autonomy in end-of-life care be portrayed as an effort to restrict patient choice?[1]

However, the concern that clinicians and insurers withhold needed care is a familiar story in the media, especially in conjunction with managed care and other settings in which physicians are incentivized to reduce resource utilization. Physicians, too, complain about systematic impediments or restrictions on patient management. Limitations on access to expensive diagnostic and treatment options are likely to become more common with cost-reduction reforms in the health care system, heightening such concerns. Though the notion of "death panels" may be misleading, public suspicion about the benevolence of the health care system in managing end-of-life decisions lends credence to such an uproar[2].

ARE ADVANCE CARE DIRECTIVES EFFECTIVE AND SAFE?

The goal of advance care planning is to promote the autonomy of decisionally incapacitated patients when they face choices about life-sustaining treatments. Instructional advance care directives (ACDs) or living wills have been widely promoted,[3] and have been available in as many as 68% of decisionally incompetent elderly patients who

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required choices about life-sustaining treatment.[4] However, there is insufficient evidence of the effectiveness of ACP.[5–9] Importantly, the safety of this common procedure has not received deserved scrutiny.

Avoiding unwanted "aggressive," harmful or non-beneficial treatments is a serious and increasingly common concern shared by patients, families, and health care providers.[10–12] While the movement to promote advance care planning focuses on preventing scenarios where unwanted aggressive care is provided, physicians often err on the side of withholding life-sustaining treatments when patients have advance care plans indicating a wish for aggressive treatment.[13] In one study, only 5 of the 10 patients wanting aggressive care received treatment consistent with their wishes.[4] Thus, both overtreatment and undertreatment are concerns.

Reassuringly, recent studies suggest a positive impact of ACP on patient and family satisfaction and multiple measures of their well-being and on rates of completion of ACDs.[4,14–18] However, credible approaches to measuring concordance of clinical outcomes with informed patient wishes remain elusive.

An important recent study on ACP followed 309 decisionally competent patients aged 80 or more.[15] Participants were randomized to receive usual care or usual care plus facilitated advance care planning. Of participants, 84% in the intervention arm documented their wishes or appointed a surrogate or both. As might be expected, the wishes of the patients who received facilitated advance care planning and subsequently died were better documented in the intervention group ((25/29, 86%) compared with the control group (8/27, 30%; $p<0.001$). While the authors claimed that the trial showed improved agreement between patient wishes and clinical outcomes after ACP, the presence of an ACD was required in order to demonstrate concordance. A positive outcome, therefore, reflects ACP completion rather than concordance. Moreover, non-concordance was not significantly greater in the control group; only 3 of the 56 patients who died showed non-concordance: one in the intervention group, two in control. A significant finding, though, was that the intervention group's bereaved families reported significantly less stress, anxiety, and depression, suggesting that advance care planning alleviates the burden of decision making on families.

WHAT ARE LEGITIMATE CONCERNS ABOUT ADVANCE CARE PLANNING THAT NEED TO BE STUDIED AND ADDRESSED?

The goal of ACP is of undisputed value. Likewise, the benefits of discussing ACPs with one's family and physician and of thoughtfully assigning and educating a health care agent or "proxy" seems clear. Discussions about end-of-life care theoretically might enrich the patient's deliberation about future "in-the-moment" decisions.[9] However, pitfalls of the process are under-recognized.

ACDs correspond poorly with patient's care preferences.[19] After discussions about CPR, patient understanding is disappointingly low, and concordance between the recollections of the patient and the physician or health care proxy is surprisingly poor.[20–23] Patients may not even remember their choices a year later.[24] Decisions can be made despite considerable uncertainty about one's wishes, especially among minority and low-literacy patients and those considering themselves to be in poor health [25].

Hypothetical discussions have limited bearing on decisions made later when faced by a concrete situation.[26] In one large study, living wills were completed a median of 20 months before death (mean 43.5 months) with a range of 0-399 months, while health care agents were designated a median of 19 months prior to death (mean 43 months) with a range of 0-1202 months.[4] Patient preferences evolve over time,[24,27] (including among physicians [28]) and when health status changes.[29–31] Patients facing more immediate life-threatening situations or experiencing more disability tend to tolerate worse functional states and accept more life-sustaining treatments [26,30,32].

Programs like the national POLST (Physician Orders for Life Sustaining Treatment) Paradigm [33]—a movement in each state to develop a document that is legally binding across all health care sites and records choices about life-sustaining treatments, such as DNR—raise the specter that an emergency medical technician or physician, confronted by a decisionally incapacitated patient who requires CPR or intubation in order to have a chance for survival, will follow a guideline that inaccurately reflects current wishes, perhaps completed a year before when a completely different situation was imagined.

DO PHYSICIANS UNDULY INFLUENCE PATIENT CHOICES?

A physician, of course, should help inform and support patients in making decisions that reflect their values, goals, and preferences.[34] Physicians, however, tend to rate patient quality of life considerably lower than the patients themselves,[35] use different criteria for a "good death,"[36] and may be perceived at times as badgering patients and families to forego life-sustaining treatments.[37,38] Equally worrisome concerns are that physicians may abandon their patients by allowing them to make uninformed decisions, perhaps based on unrealistic television scenarios about life-sustaining treatments [39] or may offer harmful or non-beneficial treatments such as CPR when meaningful survival is unprecedented.[40]

In end-of-life care, concern (and even suspicion) that physicians may unfairly sway vulnerable patients about choosing life-sustaining treatments is not without basis. For instance, the frequency of orders to limit life-sustaining technologies in one ICU varied by 15-fold among physicians, demonstrating the huge importance of physician factors in these choices.[41] Both directions of undue influence—to reject or to accept interventions—are a concern, but the focus here is on clinicians pressuring patients to forego life-sustaining measures.

House officers have long recognized proficiency in "getting the DNR,"[42] which suggests that some patients have been bullied or frightened into rejecting CPR or simply allowed to make decisions that may not truly reflect their informed wishes. In a more sophisticated version of "getting the DNR," subjects are shown either videos of drooling patients with far-advanced dementia or grotesque portrayals of CPR for a cancer patient, and they then dramatically reduce their preferences for aggressive end-of-life care.[43,44]

SAFEGUARDS AND PUBLIC POLICY

The "death panel" scare and more substantial evidence cited above suggests that safeguards for our patients completing ACDs deserve more attention. Finding a balance between respecting patient autonomy and avoiding pitfalls that may undermine patient autonomy will be challenging. A few suggestions can become the foundation for a more nuanced approach to ACP and for empirical research.

A Range of ACP Procedures are Required. One size does not fit all. ACDs may range from general statements of values to such specific orders as DNR, do not intubate, do not hospitalize, do not provide artificial hydration or nutrition, or do not administer antibiotics. Different situations, including different stages of health and illness, demand different types of ACDs, and thus require both different conversations and different training in leading such discussions.

One major distinction is between choosing and educating a health care agent *versus* preparing an ACD. Another important distinction is between urgent discussions when decisions about treatment may be imminent *versus* more theoretical discussions about the future. For instance, chronically or terminally ill patients and the elderly are at high risk for facing decisions about life-sustaining treatments, and their experience of illness may provide a context in which they can make reasonable choices for themselves. Conversely, our society may not even wish to allocate limited resources in order to anticipate those very few instances when life-or-death decisions have to be made for previously well persons who might have made abstract hypothetical choices beforehand. Indeed, ACDs are rarely relevant for healthy younger patients, though they may want to choose a health care agent and document some guidance about care in the face of severe loss of mental capacity.

ACP promotion should also recognize that many cultures frankly object to talking about dying.[45] The process of ACP should respect religious and racial variations in preferences about discussing and deciding about end-of-life care.[46–49]

Avoid Simple Solutions. No advance directive should include vague instructions like "No heroics" or "No extraordinary care." Forms that deal only with whether to carry out a procedure like CPR are handy shortcuts that can also short-change our patients. Certainly, some patients, usually the chronically ill elderly, may have clear wishes to forego any life-sustaining treatment, while patients of all ages may wish not to be kept alive in the face of an irreversible condition that precludes meaningful human interaction. But most medical decisions are not so simple.

As has been repeatedly noted in the current literature, ACP should avoid focusing initially on procedures or methods (e.g., CPR, intubation) but rather address values, goals, and preferences (e.g., prolonging life and preserving mentation *versus* minimizing suffering and avoiding undignified states or an unacceptable functional status).[50–52]

Facing Emergent Situations, Err on the Side of Preserving Life. For the code status decisions and similar life-or-death decisions in urgent situations, a first tenet would be to err on the side of preserving life whenever an ACD (or in the absence of an ACD, when the substituted judgment of the family or health care agent) does not convincingly address the current clinical situation. For example, did the patient anticipate a medical crisis, prognosis or treatment option significantly different than currently faced? Was the directive completed in the distant past and is thus difficult to apply to the present circumstances? While failing to respect an ACD harms the patient, failing to preserve life can cause irreversible harm. Some decisions to limit life-sustaining technology can reasonably be deferred, though potentially at considerable cost to the patient, family, and health care system. Unless meaningful survival would be unprecedented, a time-limited trial of aggressive treatment may be considered when the applicability of an ACD is seriously questioned and cannot be confirmed by the health care agent or family.

In order to interpret ACDs and respect patients' wishes, physicians need to appreciate the above-mentioned vagaries of ACP and the challenge of crafting a directive that truly reflects the patient's values.[53] This takes time and skill.

Advance Care Directives Apply Only to Decisionally Incompetent Patients. Relying on an advance directive to make decisions for a mentally competent patient is inappropriate. Always let the competent patient speak. Clinicians should also recognize that the decisional capacity of seriously ill patients may, at times, be subtly impaired, and these patients should be protected from making emergency choices that do not reflect their true wishes.[54]

Non-Emergent Situations Allow for a Deliberative Process. In contrast to decisions made in emergency situations, directives made in repose, such as might have been provided by Terry Schiavo before her terrible brain injury,[55,56] and especially by many chronically ill or elderly patients for whom the issue of foregoing treatments has saliency, are more subject to safeguards. Spending a median time of one minute on DNR decisions, as has been documented in one hospital recently, is a travesty.[57]

A Well-Informed Health Care Agent May Be Preferable to an ACD. Patients may choose not to engage in ACP and to avoid hypothetical discussions, deferring some or all decision making to their family, surrogate, or physician.[58,59] A well-coached and well-chosen proxy should be able to assess the complexity of the immediate medical situation, grapple with knotty medical decisions, be assertive with doctors, and make difficult choices in a stressful situation.

Non-Emergent ACDs Should Be Reviewed. Given the well-documented vagaries in ACP, any non-emergent decision to limit life-sustaining treatments (but not to accept them) should be followed by a review that assures clear, shared understanding between the patient and the recipients of the directives. Ideally, this discussion would involve a neutral second party—not necessarily a physician—who is knowledgeable about end-of-life decision making and proficient in assisting patients with these decisions. (A second opinion is always sensible when there are concerns that the patient lacks mental capacity for serious decisions or is subject to coercive influences.) A model advance care planning initiative, Respecting Choices®, has provided exemplary training for non-physician coaches, focusing on obtaining a "values history."[60] Non-physician visits have proven very useful in the hospital after a physician initiates the ACD discussion and provides information tailored to the patient's medical situation.[61]

Directives Should Be Current. ACDs need to be updated regularly, especially when health status changes; annual renewal should be required, at least for older and chronically or terminally ill patients at high risk for needing to make life-or-death decisions.

ACDs Require Physician Input. (or the input of qualified nurse-practitioners or physician assistants). Informed patients are experts on their own preferences, while physicians are experts on the probable outcomes of various management decisions and the procedures or methods to achieve the patients' goals. Trained non-physicians—nurses, social workers, chaplains, and volunteers—can be enormously helpful in ACP, but a medical perspective on the situation—particularly the prognosis and treatment options—is almost always of central importance in beginning these discussions.[61]

Clinicians Need Training. Clinicians have not been well trained to provide the expert assistance patients need to create good ACDs [62–68] or even to open up the topic.[64] The model ACP process described in the clinical literature may have little bearing on actual physician practice. Doctors tend to focus on diagnostic and treatment methods rather than attending to patient values, goals, and preferences. Clinicians spend strikingly little time on these important decisions and fail to cover essential issues.[57] Discussions seem to be unstructured and without clear objectives.[69] Physicians do not reliably provide appropriate prognostic information,[35,57] offer recommendations, focus on life goals,[57] or address adverse functional and cognitive outcomes.[30]

Thus, physicians require educational programs that focus on communication skills.[66,70] Certification for the ACP procedure should be considered. Clinicians may benefit from clinical guidelines and structured formats for such discussions, perhaps using a checklist.[71] The quality of complex, preference-sensitive treatment decisions can be improved by system support aids.[72] Physicians also need to be given the time to carry out these discussions. Finally, clinicians should never have perverse incentives, especially financial rewards, to complete such forms or to otherwise favor a particular decision on the part of a patient.

FORMULATING A RESEARCH AGENDA

Intervention studies are needed to demonstrate convincingly that ACP improves the concordance of patient wishes with outcomes of care. Additional research should deal with such serious and unsolved problems with ACP as:

- effectively educating the public about the purpose of ACP;
- understanding and addressing the low rates of ACD completion in minorities;
- improving techniques for eliciting patient values, goals, and preferences relevant to end-of-life decisions;
- developing methods (such as learning aids, decision aids, structured formats for discussions, or checklists) that help assure that patients base their decisions on their personal values and on good information about their management options;
- making readily available the relevant prognostic information (e.g., outcomes of CPR in specified health conditions) and identifying how patients can best appreciate such statistical information;

- determining what learning aides and forms best translate patient wishes into language that accurately guides physician management;
- identifying systems for reviewing decisions at regular intervals and especially with changes in health status or in emergency situations;
- evaluating and improving training of clinicians and paramedical personnel for the tasks of assisting patients in ACP and the completion of ACDs;
- developing systems that make ACDs readily available when needed, including when a patient transfers between sites, and that facilitate easy, reliable placement of documents in such a repository;
- and finally studying the process and outcome measures that will help us further evaluate and improve standardized, replicable, and disseminable approaches to ACP.

CONCLUSION

Advance care planning regularly deals with major life-or-death decisions. Procedural safeguards are appropriate both for promoting excellent clinical care, addressing patient and public concerns about limiting life-sustaining treatments, and assuring safety. Taking seriously the concerns underlying the scare over "death panels" and recognizing the vicissitudes of patient decision making about end-of-life care may help refine advance care planning as a fundamental and deeply serious clinical task for promoting patient autonomy.

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