Strategic Targeting of Advance Care Planning Interventions
The Goldilocks Phenomenon

J. Andrew Billings, MD; Rachelle Bernacki, MD

Strategically selecting patients for discussions and documentation about limiting life-sustaining treatments—choosing the right time along the end-of-life trajectory for such an intervention and identifying patients at high risk of facing end-of-life decisions—can have a profound impact on the value of advance care planning (ACP) efforts. Timing is important because the completion of an advance directive (AD) too far from or too close to the time of death can lead to end-of-life decisions that do not optimally reflect the patient’s values, goals, and preferences: a poorly chosen target patient population that is unlikely to need an AD in the near future may lead to patients making unrealistic, hypothetical choices, while assessing preferences in the emergency department or hospital in the face of a calamity is notoriously inadequate. Because much of the currently studied ACP efforts have led to a disappointingly small proportion of patients eventually benefitting from an AD, careful targeting of the intervention should also improve the efficacy of such projects. A key to optimal timing and strategic selection of target patients for an ACP program is prognostication, and we briefly highlight prognostication tools and studies that may point us toward high-value AD interventions.

Author Affiliations: Cambridge Health Alliance, Boston, Massachusetts (Billings); Massachusetts General Hospital, Boston (Billings); The Dana Farber Cancer Center, Department of Psychosocial Oncology and Palliative Care, Boston, Massachusetts (Bernacki); Division of Aging, Brigham and Women’s Hospital, Boston, Massachusetts (Bernacki); Ariadne Labs, Boston, Massachusetts (Bernacki); Harvard Medical School Center for Palliative Care, Boston, Massachusetts (Billings, Bernacki).

Corresponding Author: J. Andrew Billings, MD, Harvard Medical School Center for Palliative Care, 1½ Hilliard St, Cambridge, MA 02138 (jbillings@partners.org).

Advance care planning (ACP) includes discussing choices about end-of-life care with clinicians, family, and others; choosing and educating a durable power of attorney for health care; and ideally making informed decisions about limiting or accepting potentially life-prolonging treatments near the end of life, perhaps as documented in an advance directive (AD) or related clinician orders such as a do-not-resuscitate order (DNR). Two major strategic concerns for promoting quality in ACP discussions and AD documentation, while also wisely shepherding limited resources and achieving greater value in AD efforts, are discussed below: (1) the challenge of getting the right timing for discussions about limiting life-sustaining treatment such that the documents or orders that might be used to make choices for a decisionally incapacitated patient accurately reflect the current values, goals, and informed preferences of that patient; and (2) the related need for careful targeting of interventions to efficiently reach patients who are likely to benefit from an AD. We then discuss the use of prognostication instruments as tools to improve AD efforts.

The Timing of ACP: The Goldilocks Phenomenon

As we know from Goldilocks’ adventures in the home of the 3 bears, this finicky eater found the soup too hot, too cold, or just right. Likewise, decisions about limiting life-sustaining treatment can occur too early, too late, or at just the right time.

Too Early
A host of data indicates that patients’ preferences vary over time and that choices about life-sustaining treatments are context dependent: different preferences are expressed when patients are healthy and presented with abstract, hypothetical choices about a distant future, compared with when they are ill and truly faced with a serious illness that may portend the end of life.1 In general, patients choose more aggressive care early on.

Patients execute ADs with considerable uncertainty about their choices, including uncertainty about what their decisions mean.2 A focus on “living wills” that offer multiple clear-cut circumstances and options for care may lead to misleading choices.3 Many patients cannot accurately recall their choices after a year,4 and patients (including physician-patients) regularly change their minds about ADs over the course of a year or two.5,7 In a national cohort of long-term care nursing home residents who were followed for 5 years after admission, of those who entered requesting cardiopulmonary resuscitation, 40% changed their minds to DNR order.6 The most important factors influencing change were hospitalization and nursing home transfer.

The interval between completion of an AD and death can be long. In a nationally representative sample of elderly patients (mean age at death, 83 years), the mean duration between completing an advance directive and death was 61 months (median, 37 months).9 In another study, living wills were competed a median of 20 months before death (mean, 43.5 months), with a range of 0 to 399 months, while a health care agent was designated a median of 19 months prior to death (mean, 43 months), with a range of 0 to 1202 months.10 The popular Physician Orders for Life Sustaining Treatment (POLST) forms recommend, but do not require, revisiting decisions on a regular basis or when the patient’s condition changes.11

We found no data on how often decisions documented in ADs are reviewed, but making life-or-death decisions based on an AD...
created 5 years ago or even a year ago when the patient was not experiencing a life-threatening illness may violate the fundamental goal of ACP: to assure that care near the end of life is congruent with the informed patient’s wishes. Advance directives prepared too early and without a mechanism to refresh them regularly risk inaccurately reflecting the patient’s choices at the end of life, and their use may lead to a medical error.12 Advance directives need to be refreshed regularly, probably at least annually for patients facing an imminently life-threatening illness, as well as whenever a serious life-threatening medical condition develops or changes significantly.

Too Late (or Never)
Research on patients with multiple life-threatening conditions, as well as many clinicians’ experience in daily hospital practice, indicate that ACP is simply not done13 or often goes on in the emergency department or hospital when a medical crisis arises,14 even on the day of death.15 In one study from an academic medical center, only 20.3% of patients with metastatic cancer had a documented code status.16 Even when patients with advanced lung cancer were prompted electronically to complete an AD, only 34% had a code status.17 Part of the problem seems to be that patients simply do not want to think about end-of-life decisions or complete ADs, even after educational interventions,18,19 and overall completion rates for ADs are low, though apparently increasing significantly.

Getting timing just right is, of course, a challenge. Not only the immediacy of death but also a host of situational, religious, cultural, educational, and other factors determine whether a particular occasion and a particular kind of discussion are appropriate. We found no data on optimal timing for documenting ADs or even how expert, motivated clinicians decide to discuss or document such decisions. As discussed in the following section, we believe a better ability to prognosticate may improve targeting.

While we focus here on targeting of interventions, we also have raised concerns above about the quality of ACP discussions. Clinicians have generally not been trained to carry out such discussions.20–22 On the basis of our literature review, we outline ideal features of well-timed ACP in the Box.

“Just Right” Timing and Strategic Patient Selection: The Importance of Prognosis
The right time to discuss end-of-life planning depends on many factors, but one key factor is the patient’s prognosis. Prognostic stratification can identify groups at high risk for facing end-of-life decisions and thus for whom targeted interventions to discuss ACP and to create ADs may be useful. Clinically, any change in prognosis, as occasioned, for instance, by an emergency transfer from a nursing home to the hospital or development of a new serious or life-threatening condition, calls for a fresh discussion of goals of care. Unfortunately, prognostication is difficult and empirical data do not offer the precision that clinicians desire, but some tools are presented here.
Many patients want to discuss prognosis with physicians: inadequacy of prognostic information is often the greatest complaint patients and families have about end-of-life care. Despite the importance of prognosis, physicians are often reluctant to prognosticate. In a national survey of physicians, 90% believed they should make choices about specific methods of life-sustaining care. Moreover, 57% felt inadequately trained in prognostication. The accuracy of physician prognostic skill has been shown to be poor. In one study, physicians were asked provide survival estimates of terminally ill patients at the time of hospice referral: physicians were accurate 20% of the time and overestimated survival by a factor of 5.3. In addition, longer physician-patient relationships were associated with decreased prognostic accuracy.

Building in “triggers” that help identify patients who, on average, have less than 1 to 2 years to live may help to remind clinicians to conduct ACP discussions; such a system could ideally be embedded in electronic medical systems (EMR). For example, e-mail prompts were used to trigger clinicians to document code status in patients with advanced solid tumors, and at 1-year follow-up, 33.7% had a code status document in the outpatient EMR compared with 14.5% of historical controls.

The Need for Prognostic Models

Many different pathways lead to death; the last 6 to 12 months of life for some illnesses, like cancer, are slightly more predictable than, for instance, heart failure or dementia. Most patients die of acute complications of a chronic condition such as organ failure (approximately 20% of deaths). Patients with dementia or frailty (approximately 20% of deaths) may have long periods of debility with unpredictable courses. The “Surprise Question” has proven to be a useful method of identifying patients at high risk of dying soon, at least among patients with advanced cancer and dialysis patients. Physicians simply ask themselves, “Would I be surprised if this patient died in the next year?” The hazard ratio of death in 1 year for patients with cancer whose clinician answered “no” to the Surprise Questions is 7.9, and for those undergoing dialysis, 3.6.

A number of studies identify triggers that could productively target timely discussion of ADs or selection of high-risk patients. For instance, hospitalization often indicates a major health transition for elderly patients. Using only 6 accessible variables (sex, congestive heart failure, cancer, creatinine and albumin levels, and Activities of Daily Living—dependency at discharge), the Walter prognostic index stratifies older adults (age >70 years) according to 1-year mortality after hospitalization. Notably, age did not predict mortality in this older cohort.

Life expectancy tables can give rough estimates of prognosis but prove surprisingly unhelpful. Even at age 95 years, the patients in the lowest quartile of functional status have a mean survival of 1.1 years, compared with 2.5 years for the middle 2 quartiles.

A number of disease-specific prognostic models exist including the Seattle Heart Failure model, the model for end-stage liver disease (MELD), and indices for renal failure. However single disease models are problematic because many patients with chronic illness have multiple comorbidities. In fact, 48% of Medicare beneficiaries 65 years or older had at least 3 chronic medical conditions and 21% had 5 or more. A helpful prognostic toolbox that incorporates multiple comorbidities is available at http://www.eprognosis.org.

Advance care planning program planners can use prognostic indices to identify appropriate patients. These tools can also lend confidence to clinician judgments about prognosis and provide an objective measure that supports clinical intuition (eg, the Surprise Question). Combining clinical estimates with prognostic indices may result in more accurate estimates than either alone. More research is needed in this area, including for the use of clinical triggers.

Caveat: How Else Might ACP Benefit Patients and Families?

We have based our evidence about the effectiveness of ADs on a single outcome: congruence between patients’ wishes for end-of-life care and the care they actually receive. However, this approach should not negate the importance of other potentially beneficial outcomes. Initiating ACP well before patients are facing end-of-life decisions may serve the function of introducing the conversation and opening communication about these matters with the family, health care agent, and clinical team. Fried et al and Sudore and Fried have suggested that the value of ACP discussions might be judged by how early discussions prepare patients and families for later decisions—their “just in time” choices. This approach is embodied in the highly regarded Respecting Choices paradigm that includes the following: “First Steps,” a routine discussion that normalizes such conversations in a general population; a “Next Steps” that begins ACP for patients with chronic progressive illnesses who are facing decline or complications and who might have clear notions about their prognoses and the functional outcome of their choices; and “Last
Strategic Targeting of Advance Care Planning

Uncertainty about advance care planning treatment

Completion and use of ADs may be effective. Completed ADs are often inaccurate, too vague, not available, not used, or completed too early or too late. Of those targeted patients who die, many are not decisionally incapacitated when choices need to be made, and only a small number without a health care proxy or AD receive care incongruent with their previously expressed wishes. Aiming ACP interventions at a broad swath of patients may have a small impact on actual care, as judged by congruence between patient wishes and actual medical management, and may even lead to medical error.

Ironically, while these observations suggest a serious challenge for planning quality improvement projects, large-scale interventions, and research in ACP, the primary care clinician or specialist who is following patients longitudinally may be in a good position to target many appropriate patients for ACP. Guided by the “Surprise Question,” general awareness of patients’ risk of dying soon or the use of prognostic indices, high-risk patients with identified poor functional status and significant comorbidities might readily define a target group in clinical practice—those at high risk for death in the foreseeable future and for whom the time is “just right” to discuss and document choices about end-of-life care.

Conclusions

In planning interventions aimed at promoting ACP and ADs and related orders to limit life-sustaining treatments, the observations described here point to a great need to attend to strategic timing and selection of patients. Quality initiatives or pay for performance programs that aim for all patients to have ADs and provide insufficient clinician training in how to conduct ACP discussions are unlikely to be effective. Completed ADs are often inaccurate, too vague, not available, not used, or completed too early or too late. Of those targeted patients who die, many are not decisionally incapacitated when choices need to be made, and only a small number without a health care proxy or AD receive care incongruent with their previously expressed wishes. Aiming ACP interventions at a broad swath of patients may have a small impact on actual care, as judged by congruence between patient wishes and actual medical management, and may even lead to medical error.

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