

POLICY FORUM

For People Dying to Talk, It Finally Pays to Listen with Reimbursable Advance Care Planning

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Abstract

Whether at the beginning, middle, or end of life, health care delivery choices abound. Yet only recently have conversations specifically regarding preferences for care at the end of life become a reimbursable intervention, deemed equivalent in importance to a medical procedure. Quite distinct from other procedures, in which expectations for outcomes are explicit and measurable, outcomes have been left intentionally vague for advance care planning (ACP) conversations. This article will explore the inherent challenges of and opportunities for developing formalized outcomes, methods of measurement, and training to ensure excellence in the performance of ACP conversation procedures.

Background

When Medicare's reimbursement mechanism for end-of-life (EOL) planning became effective on January 1, 2016, it was implicit recognition of both the necessity and the value of an explicit physician-patient conversation on this topic.¹ Advance care planning (ACP) involves exploring a patient's health-related values, discussing EOL treatment options that could help honor those values, and then developing an appropriate plan and communicating it to loved ones and the medical system. The 2014 Institute of Medicine report, *Dying in America: Improving Quality and Honoring Individual Preferences near the End of Life*, detailed the clinician's imperative to help Americans navigate their EOL health care choices.² As of 2012, about a quarter of Medicare dollars were spent on beneficiaries in the last year of life for care that was sometimes ineffective and even unwanted.³ Much of this low-value, high-cost treatment could be avoided if patients had more opportunities to tell their physicians and families what mattered most to them if they were seriously ill. A 2015 Kaiser Health Foundation survey of the general public found that while 89% of patients thought a discussion with their physician about EOL treatment choices was important, only 17% had actually had one.⁴

There are many barriers to these conversations, but one major obstacle is practical: finances. An already overextended practitioner can spend hours over several appointments having these sensitive discussions, which, prior to 2016, were all unbillable. A proposal to reimburse physicians for valuable time spent on voluntary ACP

was introduced during drafting of the Affordable Care Act in 2009.⁵ Prominent conservative politicians used the provision to create opposition to the bill by falsely equating reimbursement for EOL discussions with “death panels.” The ACP provision was quickly dropped from the original bill to avoid the perception that the government would limit funding of potentially life-prolonging care to save money,⁶ but it was quietly reintroduced with strong public support in 2015. New billing codes were issued for these conversations, treating them like other medical procedures.¹ The Centers for Medicare and Medicaid Services (CMS) data for 2016, the first year that these billing codes were in effect, showed that 22 000 clinicians billed for these conversations on behalf of 570 000 Medicare beneficiaries.⁷

As is the case for any new billable procedure, well-defined measurable outcomes and formalized training must be developed. This article will explore some of the unique challenges and opportunities specific to the ACP conversation procedure that are beginning to be addressed. To begin, we first define ACP and distinguish ACP conversation as a procedure. We then discuss how we go about defining and measuring outcomes for an inherently individualized, though practically shared and somewhat unpredictable, procedure. Finally, we explore training paradigms that can support the delivery and reproducibility of high-quality ACP procedures.

What Is ACP?

ACP is the opportunity to communicate our values related to our quality of life to the people who might be put in a position to speak on our behalf should we lose the ability to speak for ourselves. Ideally, this conversation is started while we are healthy, well before any serious illness has set in. In the broadest sense, we are asking, “What makes life meaningful? What is most essential to making you who you are?” Thinking more specifically about ACP for purposes of directing medical care, it can be helpful to contextualize the question in 1 of 2 ways. For those capable of describing what matters most to them in life, a clinician might ask, “If your health were to become compromised or if time were undeniably short, what physical, spiritual, and psychosocial experiences are essential in order to preserve your uniquely defined quality of life?” Alternatively, if patients are having a hard time finding ways to describe the qualities that have meaning for them, it can be helpful to ask a different question, such as, “What is the minimum acceptable quality of life or function with which you are willing to live?”

Why is this conversation important? Because of the ever-growing number of medical interventions available, it is increasingly difficult to discern when death is approaching. As a result, people living with life-limiting illnesses often face choices between treatments that might extend time or improve quality of life but that can rarely achieve both. Therefore, rather than assuming that the ever-elusive and impossible-to-quantify “more time” is what is motivating a person to seek medical care, it is imperative that clinicians discover what defines quality of life for a patient so that they can then make

recommendations regarding treatment options that honor and support the patient's stated values. If one value is more time, for example, it becomes essential to discover what actual time the patient is imagining and why. For example, is the patient hoping to see the birth of a child or reach an important event? Such questions then ground the desire for more time in the context of quality of life, allowing medical care to be tailored to support what specifically matters most to the patient.

A clear objective of an ACP conversation is for the patient to select and formally [name a trusted surrogate](#) health care decision maker. The role of the surrogate health care decision maker (also known as the durable power of attorney or DPOA for medical decisions) is to be willing and able to advocate for the patient's wishes in the event that a serious illness precludes the patient from being able to articulate them herself. While often assumed that a patient's legal partner or family member will be the DPOA for medical decisions, this default approach might not actually serve the patient's best interests. Many family members, whether because of love or strife, become so emotionally compromised when a loved one becomes seriously ill that they lose the ability to distinguish their own wishes from those the patient had previously articulated. Facilitating [goals-of-care conversations](#) between the patient and the patient's selected surrogate is ideal for providing insight into the patient's hopes, fears, and values, so that the selected surrogate can attest to his or her ability to advocate accurately for the patient if called upon to do so.⁸ This task is far more complex than, and quite distinct from, asking the patient to simply list the abstract procedural "do's and don'ts" found in a common do-not-resuscitate (DNR) form.

Alternatively, a description of a patient's minimum acceptable quality of life or function could be an anchor point for decision making; treatment options that could not meet or improve upon that minimum would trigger a reconsideration of the balance between more time and quality time. Importantly, these discussions can serve to strengthen the patient-physician bond not only by soliciting and articulating a patient's wishes but also by reaffirming the physician's commitment to nonabandonment at a deeply stressful stage of life.

Formal documentation of ACP in the form of an [advance directive](#) (AD) can be valuable, particularly when a DPOA cannot be identified. And while no universal AD form or portability platform currently exists for medical personnel to access ADs across settings, [physician orders for life-sustaining treatment](#) (POLST) registries in several states have shown promise as a tool to both implement and measure patient-centered EOL care delivery.⁹

Measuring Outcomes of ACP Conversation Procedures: Opportunities and Challenges

Superficially, the outcome of the ACP conversation procedure seems well-defined and easily measured; a patient's values are solicited, documented, and then matched to the

appropriate health care choices when the time comes. Process measures, such as frequency or timeliness of these conversations, can be monitored. Outcome measures, such as concordance between a patient's wishes and the care received and whether the care met a patient's goals, could also be tracked. However, unlike other procedures, the outcomes of which are generally binary, the outcomes of ACP conversations are intentionally fluid. Furthermore, these discussions, which embrace the inherent uncertainty in medicine and in life, assume that treatment preferences and judgments about acceptable quality of life will change over time throughout a patient's illness trajectory. Rarely, though, do we revisit the dusty document sitting in a drawer or a safe each time our circumstances or feelings change. As much of medical care remains fragmented across settings and clinicians, it will be difficult to assign accountability for a successful ACP outcome, as no one person has absolute agency. Perhaps an even more obvious challenge to measuring the ultimate outcome (ie, did the patient die the way he or she wished?) is that the person most directly affected by the procedure is ultimately unable to comment on its accuracy. Surrogate feedback, by definition, will therefore need to be a key measure of success, and we would argue it should include clinician reflection and input for quality control, as discussed below.

Measuring the quality of the ACP conversation, as opposed to the outcome, is a nuanced process. A patient or family—or, for that matter, a physician—might never have engaged in such a discussion and therefore have little expectation as to the content and experience of it. In our experience, the difference between an excellent and an inadequate conversation has to do with the degree of connection it engenders among its participants. Meaningful engagement engenders empowerment and relief, which in turn fosters the trust that nourishes the relationship—trust that can be drawn on when an imagined health crisis arrives. The quality of a discussion is, therefore, less about how many or how thoroughly options are discussed than about how deeply and meaningfully the conversation engages participants. Sometimes the end product can speak for itself, in that a document that provides only the barest outlines of a patient's wishes might reflect an unskilled or superficial conversation. However, given that talking about death is taboo, even a highly skilled practitioner might not be able to draw much from a reluctant partner.

Next Steps: Incorporating Communication Training into Standard Practice

While community conversations are shifting social and cultural views on having ACP conversations, as evidenced by several bestselling books addressing EOL care,^{10,11} comprehensive training of medical professionals is, as yet, untapped. By assigning Current Procedural Terminology (CPT®) codes to ACP conversations, CMS implied that they are indeed procedures with indications, contraindications, and complications like any other procedure. Therefore, as with other procedures, they require skills that necessitate instruction and practice to master. As Diane Meier, who heads the Center to Advance Palliative Care, has stated, "People are not born knowing how to have these

conversations any more than they're born knowing how to do an appendectomy."¹² Approaching ACP communication training as a procedure represents a wonderful opportunity for improving its teaching while also elevating the importance of all nuanced communication skills in the medical culture.

Most procedural skills in medicine are learned through a training sequence involving didactic teaching followed by observation of a skilled clinician performing the procedure and coached practice of and by the trainee, resulting in the trainee's graduated independence. Or, more simply, the learning of most procedural skills in medicine accords the familiar mantra from medical school, "see one, do one, teach one." Learners should actively observe ACP conversations by a skilled practitioner, then engage in coached practice of how to manage conversations of increasing complexity.¹³ Structured feedback from experienced teachers, as well as real patients and families, could be used to coach both trainees and practicing clinicians on how to hold more effective ACP conversations.¹⁴ These complex communication skills should be considered so foundational that they become part of graduation and licensure requirements, just as simulations and certain types of continuing medical education already are. One could argue for ACP discussions being proctored as we do for other procedures before graduating from residency programs or when applying for privileges at new hospitals. Hands-on, experiential training is standard for cardiopulmonary resuscitation training, but not for more cognitively complex tasks such as navigating a family meeting in which complicated treatment choices and their consequences need to be matched to a patient's values. The authors as well as many of their palliative care colleagues recognize the need for additional communication training and have sought such training throughout their careers. Given the ubiquitous nature of death as part of life and therefore as part of all medical care, it would benefit our profession greatly if a life-long learning ethic concerning ACP communication skills were adopted universally.

In the End, It Pays to Start with the End in Mind

CMS reimbursement for ACP conversation procedures signifies it is time to banish the myth that talking is somehow less complex and powerful than the other things we do for patients. When caring for the seriously ill, discovering what matters most to them is central to the patient-physician relationship. Fully integrating whole person ACP into standard practice and normalizing it in our medical culture and training are key to ensuring that the care that matters to those we serve is the only thing delivered. By fully developing ACP conversations as a skilled procedure, we significantly enhance our capacity to restore the heart of medicine to a sinus rhythm.

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