Nearly everyone agrees that helping patients to plan ahead by defining their goals of care is a worthy endeavor. Those who disagree probably have the good sense to keep it to themselves. Advance care planning (ACP) is one way to aspire to the triple aim of improving care, improving health, and reducing costs, promoted by the Institute for Healthcare Improvement, the Centers for Medicare and Medicaid Services (CMS), and other organizations. The ACP process respects individuals' autonomy, as well as their rights to self-determination and privacy. ACP should improve patients' experience by giving individuals the chance to ponder, then express their personal desires, and gain a modicum of control, along with the hope that their wishes will be respected when their future medical condition requires treatment decisions to be made.

Individuals who choose less aggressive treatment options will be less likely to be subjected to unpleasant and invasive interventions, which many people rightfully fear. ACP may also reduce health care expenditures because most people, when adequately informed, do not opt for all available invasive or aggressive interventions to prolong their lives (at all costs). As data recently gathered from electronic Physician Orders for Life-Sustaining Treatment (POLST) registries revealed in Oregon, frail elders often choose comfort measures only if significantly limited interventions. However, in US nursing homes, African-American, Hispanic, and Asian residents are less likely to have physician orders for life-sustaining treatment, 3 which many people rightfully fear. ACP may also reduce health care expenditures because most people, when adequately informed, do not opt for all available invasive or aggressive interventions to prolong their lives (at all costs).

Several unanswered questions remain: Do ACP interventions increase completion of advance health care directives (AHCD)? How about discussions about ACP in general? Do such discussions increase the concordance between care desired and care received?

Dr Houben and her colleagues 4 present a meta-analysis and review of 56 studies examining interventions surrounding ACP. Their findings are not surprising: most of the studies demonstrate that these parameters are improved with a formal study intervention. Obviously, it would be very difficult to blind such studies or give a placebo intervention, so even the mention of POLST, there is evidence in the literature that completing a POLST form correlates with improved concordance between expressed wishes and care received, 4 assuming that the form itself does not necessarily reflect the depth of the conversation around the decisions made. A POLST form is only as good as the conversation(s) that preceded it. Nonetheless, although the current piece makes no mention of POLST, there is evidence in the literature that completing a POLST form correlates with improved concordance between expressed wishes and care received, 4 assuming that the form does indeed reflect the patient’s wishes. Another benefit of POLST paradigm forms is that they are valid orders that can travel with the patient, and are intended to have the force of law behind them in all care settings.

Dr Houben and colleagues 4 make another important point in reminding us that AHCDs and other ACP documents should be periodically reviewed, ideally in an outpatient setting, when people are in their usual state of health, at all ages. How many times have we seen a person who, while she is a vigorous 65-year-old who plays tennis 3 times a week, completes an AHCD that indicates the desire to prolong life; then, suddenly, fast forward 20 years and she is suffering from congestive heart failure, significant chronic kidney disease, and moderate dementia (life has a way of creeping up on us that way), but never took the time to modify her AHCD to reflect her change of heart when she still had decisional capacity? One can only hope that her designated agent in the document will make treatment decisions in accordance with patients' previously expressed wishes. In post-acute and long-term care settings, historically some sort of form indicating their desire to receive or refuse various treatments (eg, tube feeding, cardiopulmonary resuscitation [CPR]) has been offered to skilled nursing facility residents and signed by their physicians. In fact, CMS requires that these discussions be offered (42 CFR §483.10[B][4] and [8]) 5 in nursing homes, and in 2012 revised the guidance to surveyors in F-Tag 155 5 with input from AMDA.

In many states that now have POLST paradigm forms (MOST, MOLST, POST, COLST, and other variants), skilled nursing facilities offer these forms to all patients, which ideally should prompt diligent and conscientious discussions with clinicians, but doesn’t always. One problem that has been identified is that the form itself does not necessarily reflect the depth of the conversation around the decisions made. A POLST form is only as good as the conversation(s) that preceded it. Nonetheless, although the current piece makes no mention of POLST, there is evidence in the literature that completing a POLST form correlates with improved concordance between expressed wishes and care received, 4 assuming that the form does indeed reflect the patient’s wishes. Another benefit of POLST paradigm forms is that they are valid orders that can travel with the patient, and are intended to have the force of law behind them in all care settings.

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consistent with what she would have wanted *in these circumstances*, but this may create conflict that would have been avoided with diligent periodic reassessment of her goals of care and updating of the AHCD or Living Will. Some advance directives specify how much leeway the agent is to be given, but in real-life situations, it is not rare for health care providers to follow the direction of the agent regardless of how much leeway is granted, even if the direction contradicts the advance directive.

This difficulty is even more problematic in the unbefriended incapacitated patient, in whom it may be impossible to determine substituted judgment, and where in many jurisdictions there is no simple mechanism to determine what would constitute this patient’s best interest. Among the studies reviewed for Houben and colleagues’ piece, there were only 3 that specifically dealt with dementia. Clearly, timely ACP can be vitally important for a person who will develop dementia, where the need for making these decisions in *advance* (while the person still has decision-making capacity) is self-evident. Moreover, dementia is a looming public health crisis with crushing cost implications, both financial and in terms of human suffering. More work is needed to encourage widespread formulation of advance directives, including those that address dementia specifically, and to facilitate decision-making processes for patients who did not complete an ACP when they had capacity and are now in the throes of significant dementia. There is work being done currently by Terman and others to assist in diligent ACP for future dementia, and viable solutions to this dilemma are welcomed. Dr Houben and her colleagues’ recognition that the actual discussions around ACP and end-of-life decisions are of critical importance is on target. Although ACP has been politicized with talk of “death panels,” it is clear that truly informed decision making in this arena is only as good as the information that our patients receive. Volandes and colleagues’ demonstrated that when people are shown a video of CPR (even just on a mannequin), they are much less likely to choose this as a desired intervention. Although most of us as health care professionals know only too well how violent, invasive, and frequently futile CPR is in a frail elderly patient, some of us may not have the time or inclination to explain this to our patients and their families. The same consideration applies to tube feeding in advanced dementia. Our health care system has a huge workforce shortage with respect to physicians and other clinicians in palliative care, and we need to come up with solutions, including education of both primary care and specialty providers on how to have these discussions, an improved mechanism to compensate providers for time spent on this very worthwhile task, and increased training in palliative care both in general postgraduate training and by expanding the number of palliative care fellowships available. Widespread recruitment and mobilization of our primary care providers to help our patients with ACP and palliative care would be ideal, but under our current system may not be a realistic goal. An example of a tool to decrease the burden on the primary care physician is the development of a family booklet about comfort care in advanced dementia, which was tested in the Netherlands, Italy, and Canada.

Several organizations, including the Coalition for Compassionate Care of California, have plain-language, low-health-literacy documents to help explain some of the burdens versus benefits of treatments like CPR and enteral feeding that can be very helpful in day-to-day practice with respect to ACP decisions. The public’s impression of the success rate of CPR (and the kind of shape people are in after receiving it), thanks in large part to the entertainment industry’s portrayal of it, is wildly optimistic. And many people believe that death from hypovolemic shock related to dehydration is horrific, when there is ample evidence to the contrary (it appears to be a peaceful death, usually without significant dyspnea or nonverbal signs of pain), and in fact it appears a much more benign exit than most of its alternatives that we see in common clinical practice. It would behoove us to educate our patients, and the public, about these important factors when completing ACP for themselves.

There are also numerous public engagement efforts by a variety of organizations, including the Conversation Project and Prepare, with tools to assist people in having these discussions with their families, such as “around the dinner table,” and their health care providers. There is a renewed interest in death and dying, including such concepts as “Death Cafes,” and it has been refreshing to see less emphasis on political correctness in talking about these subjects (there was a time not so long ago that we were chided for using terms like “end of life” for fear that they would “turn people off” or frighten them). Such grass-roots initiatives may prove to be another valuable tool in expanding the reach of ACP, and these efforts are appreciated.

With the explosion of mortality data that are now readily available, our ability to predict prognosis (and life expectancy) has improved considerably. Not every patient wants to know the answer to “How long do I have, doc?” but many do, and we have a responsibility to share the information when they do. Innovative applications and algorithms like ePrognosis (www.ePrognosis.org) have been developed to help clinicians inform their patients so they have realistic expectations and can make appropriate plans for the future, and we anticipate further refinement of such tools. It is reasonable to believe that these also will promote effective ACP and end-of-life decision making.

Interestingly, considering the authors are from a country (the Netherlands) where physician-assisted dying is legally sanctioned, there was no mention of this option, which certainly has relevance to any discussion of ACP. There is increasing public clamor for this option, although as of now only 5 US states allow it (by law or by legal precedent). Voluntary refusal of food and fluids (VRFF, also sometimes referred to as voluntary stopping of eating and drinking [VSED]), considered an ethical option for people, is a relatively benign way to die, but is not discussed in this piece, nor is palliative sedation, which is also considered ethical in cases of unbearable suffering. These are other ACP options for end-of-life care that unfortunately are rarely discussed by clinicians, in my experience, and because of that they are not made available for people who would truly benefit from them.

Ultimately, each of us has our own unique life story and path, our own set of experiences with chronic illness, disability, and death in our own circles of humanity, and our own individual ideas about what is important as we age, as well as what constitutes a reasonable or desirable quality of life for ourselves. Every person should consider his or her own goals of care for the future, and talk to his or her family about them. Memorialize your conclusions in a legal document, like a Living Will (everyone older than 18 is encouraged to have an AHCD), and be sure that the person or people you choose to make decisions on your behalf will be able to make those difficult decisions, in either direction, in accordance with what you would have wanted. And make sure you know the same information about your own loved ones. If you aren’t sure how to do this, the Internet has plenty of guidance, and most of it is reasonably good (author’s opinion only!).

If you haven’t already completed your own ACP, you might be surprised how much additional insight it will give you when you are at a patient’s bedside. And it will likely help ensure that you will get what most people desire for ourselves and others: to get the care we want to get, and not get the care we don’t want to get. That is truly what ACP is all about, and we need to get busy making it happen. When we recommend ACP interventions to our patients, we should be able to ask them to do as we do, not merely do as we say: leading by example. Thanks to Dr. Houben and her colleagues for reminding us of this important work we do on behalf of those we look after, and should do for ourselves and with our own families.
References