How Policy During the COVID-19 Era has Impacted Advance Care Planning, and What Still Needs to be Done

Individuals and their families who are at highest risk for complications from this COVID-19 health crisis are feeling especially vulnerable now. No one knows who will get sick, or how sick they will become. Or whether they would want to go to a hospital or be put on a ventilator. But there is a way to take some control, and that’s by choosing a health care agent and having a conversation to make clear all preferences regarding future care. Sharing this information gives everyone involved — patient, loved ones and providers the confidence to make decisions that abide by those personal wishes. This process is called Advance Care Planning (ACP).

Reports from health systems and providers all over the country show how important it is for all of us to discuss our health care goals now. As hospitals and other medical facilities deal with an influx of seriously ill patients, a common challenge is having the time for these important care discussions. Not having specified medical goals in advance increases the burden on frontline health care providers and families by creating confusion around medical decision-making.

Policy Action Taken Since the COVID-19 pandemic…

As this public health crisis continues, policymakers have taken historic steps to address the needs of our communities and of the seriously ill population. One of the most impactful changes has been removing policy barriers around the use of telehealth, which has resulted in an unprecedented boom in virtual care.

As part of this historic policy response around telehealth at the federal level, The Center for Medicare and Medicaid Services (CMS) recently released waivers that allow payment for ACP conversations between Medicare beneficiaries and their providers using audio-only technology (i.e. telephones). Previously, in order for a provider to get paid for having one of these virtual conversations, the interaction had to be carried out using technology that has both audio and video capabilities (i.e. Facetime, Zoom, etc.). As a matter of equity, requiring video connection for these ACP encounters had the effect of limiting access to this important service for a number of already underserved groups that have historically low levels of ACP experience, including economically disadvantaged individuals and those in remote and underserved areas. Many in these communities do not have smartphones or reliable access to high-speed internet service, so the allowance for audio-only is an important policy action that addresses the disparities that are so pronounced throughout this emergency.

At the state level, where most of the policy action around ACP takes place, there have also been important steps taken to ease access during the crisis. Specifically, a number of states have issued Executive Orders that waive or modify regulations & guidance around the requirements that certain legal documents, including advance directives, must be witnessed and/or notarized in-person. Given how COVID restrictions have made in-person interaction much more difficult,
most of these orders now allow for digital witnessing and remote notarization using technology to meet these legal requirements (see a list of state-by-state rules on remote notarization here). However, it is not always clear in every state order what the specific impact on ADs are, so it is important to review the details of the orders closely and reach out to the state department of health for additional clarity you may need. And while many states have pursued these AD-related flexibilities, many have yet to take action, which is an opportunity for state-level advocacy by ACP champions and stakeholders.

Despite these positive policy changes, and a wider recognition of the benefits of ACP, additional policy barriers exist that continue to make it challenging for people to receive these vital services. Given the importance of these conversations to helping seriously ill individuals and those who matter most to them have a higher quality of life, additional policy action to overcome these barriers continues to be a priority.

**What Policy Changes Still Need to be Made?**

**Remove cost-sharing and deductible payments**

At present, most Medicare ACP conversations have cost-sharing and deductible payment requirements that patients are responsible for. When these discussions are initiated by specialists that have even higher co-pay rates, some of the sickest patients are being asked to pay upwards of $70 for a vital conversation about their treatment wishes. Given the especially strained financial circumstances the pandemic has imposed on individuals, and communities, it is important that any and all cost-related barriers to these ACP services be removed, especially for older Americans and other Medicare beneficiaries who are susceptible to COVID-19. We need to ensure that cost doesn’t hinder access to these critical conversations between individuals and their medical team.

**Expand the types of clinicians who can get paid to have these conversations**

Currently, only physicians, nurse practitioners, and physician assistants can bill directly for Medicare’s ACP services. During this uniquely challenging time, when knowing patient goals are crucial, there simply aren’t enough qualified providers eligible to bill for these services. We need to tap into the skill and capacity of our clinical social worker and nurse workforces, and empower them to facilitate these conversations and be reimbursed for doing so.

**Restore Patient Self Determination Act Requirements (Advance Directives):**

As part of a batch of COVID-19 flexibilities, CMS recently issued a problematic waiver that is allowing hospitals during the pandemic to skirt the Patient Self Determination Act of 1990 (PSDA) requirement that they inform patients of the facility’s policies on advance directives. This waiver was created to save hospital staff time, but it could create a more difficult challenge to sort out a patient’s wishes after admission. The consequence of not having a clearly identified health agent – a person authorized to participate in clinical decision making for individuals too
sick to participate themselves – can result in time-consuming efforts to determine who should make those decisions for the patient and what the right treatment options following admission might be. Asking families and loved ones to make “group decisions” in a crisis is hard even when in-person discussions are possible. But with COVID-19, visitation is now limited and so those conversations have to happen remotely. Being put in the untenable position of having to make difficult decisions for patients – without clear direction from them – only increases the stress on all involved. Therefore, CMS should reinstate the requirements under the PSDA to require hospitals to inform patients of their advance directive policies.

This will be especially important as hospitals begin to carry out previously postponed or canceled elective and non-COVID procedures. In a recent joint statement on resuming elective surgery from the American College of Surgeons, the American Society of Anesthesiologists, the Association of periOperative Registered Nurses, and the American Hospital Association, the groups state that an “advanced directive discussion with a surgeon, especially for patients who are older adults, frail or post-COVID-19” is a key consideration for facility policies.

Click here for a pull-out summary and contact details to provide feedback to CMS on this waiver.

Ensure that ACP documents are honored and recognized across state lines:

Ensuring that someone’s advance directive follows them and remains valid wherever they go is important, especially during the COVID-19 emergency. Patients must be confident that their care goals will be known and honored by providers and health care institutions no matter where the directive was created. The lack of state-to-state transferability of ACP documents should be remedied to ensure that a person’s values and treatment preferences go where they go.

Summary

Now, more than ever, is the time for the healthcare system to engage patients in thoughtful conversations about serious illness care. While COVID-19 is spurring the public’s interest in ACP, it is also creating new challenges to carrying these discussions out, many of which must be tackled at the state or federal policy level. At a moment when ACP has taken on perhaps its highest profile in the national conversation, we need advocates to understand that there are structural barriers to its scale and spread, and we must push our policy leaders to take action to address those barriers.

Advance care planning will be a central topic of discussion during C-TAC’s National Policy Forum, taking place from 1 – 4 PM ET on Wednesday, June 24. Join us for this free, virtual event as leaders and innovators in the field share in-depth insights and updates on the ways in which the COVID-19 pandemic has re-shaped the policy landscape for serious illness care. To learn more and register today, please click here.