

4 touchstones for end-of-life conversations during COVID-19

DEC 15, 2020

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The goals of end-of-life conversations haven't changed during the pandemic, but the rules around how and when they should take place have. Many patients dying of COVID-19 in ICUs are wholly unprepared for death, and they must process their dramatic decline and uncertain prognosis in an environment impeded by personal protective equipment and without the in-person help of their loved ones.

"Patients are dying alone in the hospital, and that's been a source of trauma for families and loved ones, as well as the clinicians caring for them; thus, it becomes even more important to talk with patients and care partners about goals of care," said Mark Thomas Hughes, MD. He is an internist and palliative care physician at Johns Hopkins Medicine, a core faculty member in the Berman Institute of Bioethics there, and assistant professor of medicine at John Hopkins University School of Medicine.

"To be sure, these objectives ... should be the same as what we do in non-pandemic times, but there's an urgency to having these conversations knowing the uncertainty of the illness trajectory," Dr. Hughes said.

The COVID-19 pandemic is bringing new medical ethical questions to the forefront. The AMA is your source for guidance on ethical issues like triage and resource allocation during COVID-19.

How to bring closure

In remarks recorded for the AMA Medical Student Section's virtual gathering at the November 2020 AMA Sections Meeting, Dr. Hughes offered this advice that is instructive as well for practicing physicians and other members of the care team.

Establish rapport and build a relationship. This should always be the first goal with all patients but especially with patients with an uncertain future or who face the prospect of dying, even if conversations are hampered by face masks or working through a telemedicine platform, Dr. Hughes noted.

“It’s important to acknowledge the uncertainty of the situation and validate the fear, sadness or other emotion that the person is going through,” he said. “The clinician should discuss their recommendations for the care plan, and it is vital to hear from the patient what is important to them—both in living their lives and in making medical decisions. It’s also important to find out who the patient would want to speak for them if they cannot speak for themselves.”

Talk about how standards of care could change. “In the ethics world, a lot of the focus in the early part of the pandemic was developing algorithms about allocation of scarce resources, like ventilators and ICU beds, and whether interventions like CPR would be offered to patients,” Dr. Hughes said. “Because these guidelines may entail limitations in what is provided to patients that would under normal circumstances be offered to them, it’s important to have a game plan on how we have these conversations with patients.”

Perform a life review. This involves helping the patient—or, if the person is unconscious or unable to speak, helping family members—define his or her legacy.

“As human beings, we all strive to find meaning. We can find meaning in our experiences, in our work, in our relationships. How we define our existence and our attitude in facing illness, suffering and death can have tremendous meaning for us and our loved ones,” he said. “As a palliative care physician, I can tell you that this is not only meaningful for the patient and for the family, but it’s meaningful for the clinician as well.”

Help the patient settle things with loved ones. “Whether closure with family [happens] in person or through telemedicine, there are some key things that can always be said at life’s end,” Dr. Hughes said. “Each one may be more or less relevant to a person’s life and the relationship being considered. But these four things, plus the ability to say, ‘Goodbye,’ can be useful phrases to rely on when other words fail us. They include, ‘Please forgive me,’ ‘I forgive you,’ ‘Thank you,’ and ‘I love you.’”

Dr. Hughes’ advice on end-of-life conversations was part of a larger talk he gave about ethical challenges during the pandemic, which included guidance for physicians experiencing moral distress.