

## Episode: Ethics Talk Videocast Transcript – Advance Care Planning and End-of-life Care in the COVID Era

Guests: Helen Chapple, PhD, RN, MSN

Host: Tim Hoff; Audiey Kao, MD, PhD

Transcript by: Cheryl Green

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[bright theme music]

TIM HOFF: Welcome to another special edition of *Ethics Talk*, the *American Medical Association Journal of Ethics* podcast on ethics in health and health care. I'm your host, Tim Hoff. This episode is an audio version of a video interview conducted by the Journal's editor in chief, Dr Audiey Kao, with Dr Helen Chapple. Dr Chapple is a Professor of Nursing, Ethics, and Interdisciplinary Studies at Creighton University. Dr Chapple joined us to talk about challenges and opportunities to elicit and honor patients' health care preferences during the COVID-19 pandemic. To watch the full video interview, head to our site, [JournalofEthics.org](http://JournalofEthics.org), or visit our [YouTube channel](#).

DR AUDIEY KAO: Helen, good morning. [theme music fades out]

DR HELEN CHAPPLE: Good morning, Audiey. Good to see you.

KAO: Yeah. Thank you for being a guest on *Ethics Talk* today.

CHAPPLE: I'm glad to be here.

KAO: So, Helen, as you know, most of us don't like to think about or talk about death and dying. This social reality is reflected in estimates that upwards of two thirds of U.S. adults do not have advance directives. People with chronic medical conditions are only slightly more likely than healthy individuals by completing advance directives. So, in the best of times, it can be difficult to get Americans to talk about their end-of-life care preferences. Given this current pandemic, what do you see as the challenges and maybe even some of the opportunities to get more of us to talk about matters of life and death in advance?

CHAPPLE: You know, Audiey, you're right. It is difficult to get people to go there. I'm surprised to hear "death" on our media all the time, a word that we just rarely used to hear. And I don't know how that might be changing us in some ways because we're reminded of our mortality. So, in that sense, indeed, there's an opportunity. It's harder to put it away because we're hearing about it all the time. And it's harder to say it's only going to be somebody else. And I think that a lot of people are having this experience of knowing someone with the virus, or there's just no escaping it. So, indeed, there is an opportunity in that sense. And it could be that people who already have chronic conditions are thinking about what it might be like for them if they are caught in this situation, and they are in the ICU with no family around them. Perhaps they have and will talk a little bit more about what they would like to have done in those situations.

So, I don't know if you want me to talk a little bit about advance directives at this point, because advance care planning involves documents or can involve documents.

KAO: Yeah, I think, Helen, it would help our audience to be on the same page, so to speak, if you can just give a short primer about what advance directives are.

CHAPPLE: Advance directives are several different kinds of documents. They can be. We think about the living will perhaps most personally, because that's the part of the advance directives in which we specify what our preferences might be. But another part of the advance directive, which may be even more important, is the designation of a decision maker, a medical proxy. There are many words for this surrogate decision maker, the person who will be designated to make those decisions if you are unable to speak for yourself and you are terminally ill. So, those two pieces are part of the advance directive. Some people also believe that designation about organs, if you happen to be in a situation where you are brain dead, your directive in advance about what you want done with organs in that case is also an advance directive.

KAO: Yeah, thank you for that. If I can just follow up, you mentioned that there could be, in a unintended way, an opportunity for people to begin talking about death and dying and what their preferences are. Do you see any particular challenges that this pandemic presents in helping people express their medical care preferences?

CHAPPLE: Well, certainly there is the problem that people can't be together. So, they would have to be even more perhaps deliberate about doing it. They would need to do it over some device if they cannot be with the family that they would most be expecting to have these conversations with. We've talked about in the past the idea of having advance care planning conversations over Thanksgiving dinner, for instance, just because that's when the family tends to be together, and there aren't big celebrations besides football going on otherwise. So, but in these situations where we are so isolated, we may be considering our own mortality. We may be thinking about who we would want to make decisions for us. But it's going to be tough to figure out how we would envision those final days, because those final days are meant to be situations where we're hoping to make some meaning, and we're hoping to have suffering, any suffering very minimized. So, there's a lot, we have a lot of expectations if we are thinking in that direction.

KAO: Yeah, no. I think your point about the fact that we're physically distancing right now makes it very difficult to sort of gather around the Thanksgiving table, so to speak, as you were just saying a moment ago, to talk about these very challenging issues. That being said, I've had some people tell me that there are individuals who are making video selfies, describing what their preferences are in the event that they can't speak for themselves and sharing these selfies with their family and loved ones. And so, I guess there are some efforts in trying to bridge that level of physical distancing under these very unusual situations that we're in today.

CHAPPLE: Right. And so, of course, there are those possibilities that people will be quite innovative about how to get this done. Again, it might be, there might be a digital divide here in terms of people being aware of it. And in fact, there is a divide in terms of the advance care planning. The people who tend to be doing it oftentimes may be people with chronic illnesses, but there are also people who already have plenty of medical care, often, not always, of course.

KAO: Right.

CHAPPLE: So that they're willing to say, "Oh, yes. Well, down the road, perhaps, I don't need all of that medical care." And the people who are not well-insured and not sure of

what will happen to them tomorrow are going to be maybe less willing to engage in that practice. And they may also be less able to take advantage of some of those digital opportunities.

KAO: Yeah. So, as you were saying a moment ago, this pandemic may prompt more conversations about patients' preferences for medical care. But there are still going to be individuals who present and are admitted to the hospital without an advance directive. How should clinicians approach this situation?

CHAPPLE: Well, the very, I think the best way, the most important thing to be doing is to communicate with families. And unfortunately, while this pandemic is happening and clinicians are stretched, because families can't come and because they're not allowed to visit, the communication with families has to be even more important, more regular, more routinized, and in different kinds of ways. It has to be at least daily so that families are feeling like they are part of the team in taking care of these patients. So, it's very, very challenging, I think. And certainly, digital communication or video communication is also going to be very important here if it can be done.

KAO: Yeah, no. I mean, I think beyond just the distancing and whatever means we can engage in communication with loved ones, it's never the ideal situation when you're discussing advance directives, during urgency or an emergency, as in the case of patients who are obviously admitted to the hospital with presumed COVID. And those people are desperately ill, so it makes the whole process of understanding one patient's values and preferences that much more difficult. And I know as a long-practicing palliative care expert, this is not new to you.

CHAPPLE: Right. Now, and another challenge in this is that if these patients are on a ventilator, they are not going to be able to talk. They will be sedated. They may be paralyzed, chemically paralyzed. They will require total care. That means they'll need to be turned every two hours. They'll have to be cleaned up. They'll need to be suctioned. All the while, they will not be communicating. Because that endotracheal tube makes you feel like you're going to gag all the time, that's why they do all these, they medicate these patients so that they can tolerate the situation and not make themselves worse.

KAO: Right.

CHAPPLE: So, these patients are not, themselves, communicating at all. And they may all look very, very similar to the clinicians taking care of them. And without families present, then that differentiation is also not available. It's important to be able to do things like have, let's see, if there were boards in the room, thoughts about these patients, what are the unique characteristics of this patient as we've been told by the family? Do they have grandchildren? Can we put pictures up? Are there things that we can do that will humanize these patients for all the caregivers in a little bit more depth so that we can see them more in their fullness, the fullness of their normal lives, which they cannot live right at the moment?

KAO: Yeah, no. I think you're right that this pandemic has further isolated the sickest of the patients for those who are either intubated, and the lack of physical presence beyond those in the health care team. Any efforts that we can humanize the environment not only for the benefit of the patients who are, as you were saying, essentially under a kind of medical-induced coma because they're intubated, but maybe even as importantly to the health care team who are taking care of these individuals.

CHAPPLE: Yes. Yes, indeed. The ministry to them, to the health care providers is all important, as we know, because they're being stretched. And they're being asked, in a way, to be the family for these patients.

KAO: Right.

CHAPPLE: They have to be stand-ins for the family in a brand new way.

KAO: So, if we can switch gears a little bit and talk about when patients' preferences for medical care treatments may differ from what the health care team thinks. So, according to provisional death counts compiled by the CDC, close to 80 percent of all deaths from COVID-19 are individuals who are 65 years and older, in fact. While there is still much that we don't know about the disproportionate death rates based on age, a recent case series that included 5,700 patients in New York City found that nearly all patients over 65 who were on mechanical ventilatory support actually died. Given what we currently know and don't know, what happens if a patient says that he or she wants quote-unquote "everything done," but the health care team believes that conducting CPR is futile? And what is the role, if any, for unilateral Do Not Resuscitate or DNR orders in these situations?

CHAPPLE: Well, that's a very tough question. And we know ethically, they're not something that we would go for on any kind of a general basis. And in these cases, when these patients are so very sick, it is possible. And so, one part of the question that you're asking or one of the factors in this is that CPR involves many practitioners. One person cannot just do CPR. If there is a code called, for instance, a patient arrests either respiratorily or cardiac wise, it's a way that many clinicians must gather in order to do all of the different things that need to be done in a very, very short period of time. So, that means that you're pulling clinicians away from other patients. And you're also, in theory, if this is an ICU that's taking care of a lot of COVID patients—maybe it's COVID dedicated—all the people, all the clinicians will already be in the gear that they need to be in. So, in theory, there may be the risk of contamination is, I don't know if it's less, maybe. I would need to be practicing right now in order to know that. But it does certainly take clinicians away from other patients. And this is a very sick group in theory, so they may not, that may be more difficult to justify if one feels that a patient is not going to survive. Certainly, if these—

So, I think we need to think about the conditions that we're in and compare them to what we would be doing in a normal situation. In a normal situation, if someone goes into cardiac arrest and it's not anticipated, then we would, we as clinicians, would do everything we could do to rescue them from that situation. If these situations are in a COVID-heavy ICU unit where staff is very stretched, perhaps there is a way to say this is a triage situation. This is a different situation than normal. Someone would, some maybe group of people, would need to make that decision and say because of X, Y, and Z circumstances that are prevailing at this moment, the expectations for rescuing every person who goes into cardiac arrest have to be suspended. And then there would need to be decisions made about when those conditions change.

KAO: Right.

CHAPPLE: And I think that it is not the people at the bedside who should be making those decisions.

KAO: Right.

CHAPPLE: I think that it's ethically too difficult when you are invested in the care of the patient in front of you. It's hard to overcome that immediate expectation to rescue.

KAO: Yeah, no. I think you raise several good points. I think that even in this very unprecedented situation that we're in, having a universal DNR policy still really is not ethically defensible. And as you were just alluding to, that we need to take a more case-by-case determination. And you're suggesting that that include the non-treating clinician because it provides maybe some degree of objectivity in terms of determining whether or not engaging in CPR and engaging in interventions which can put, in this case with a respiratory pandemic, the code team under some risk are issues that are being confronted by many of those in the front lines. So, I think that your points are well made, and I think these are very challenging times. But the ethics should remain the same.

CHAPPLE: Our expectation is that we rescue people from imminent death. That's the way we have designed our health care system, and that's what we're trained to do. If those expectations are to be changed in some way, it's not up to the bedside clinician. It needs to have a broad group of people looking at it and making a decision about that. And it's made in some non-personal way to apply to more than one patient, maybe for a period of time. But our default is not necessarily a wrong one: to rescue everyone or to expect to do that.

KAO: Right.

CHAPPLE: And then to think very carefully if those expectations need to be changed.

KAO: Right.

CHAPPLE: And it would be time-limited, probably.

KAO: Sure. So, for those patients who prefer not to be intubated or go to the ICU, the need to deliver good palliative care is even more essential these days. Can you speak to how this pandemic has affected the delivery of palliative care?

CHAPPLE: I am not at the bedside myself now, but palliative care is something that would be appropriate. A palliative care referral would be appropriate for any patient that has COVID, because we know how the combination of certain factors tends to make them more vulnerable: if they're older, if they have certain comorbidities, that kind of thing. But if they're coming to the hospital at all, it means that they're unable to manage at home and that their situation is dire or could become dire quickly. So, palliative care referral makes sense. And that was obviously going to stretch the palliative care delivery people, the clinicians that are trained to do that, to a tremendous extent.

KAO: Right. Are there any—as you were saying, you've practiced in palliative care for decades, but you're currently no longer not “at the bedside,” quote-unquote—but are you aware of any good educational resources that you think those viewing this interview would benefit from?

CHAPPLE: Yes, there is. The Society for Critical Care Medicine has a website where they're talking about family-centered care, and it has a number of very, very helpful suggestions about how to deliver palliative care. And they emphasize this idea of

communication, which is a central feature of palliative care as well. So, we can perhaps offer that information for viewers.

KAO: Yeah, no. Thank you. I think that'll be very helpful. And as we wrap up our conversation today, Helen, I'd like to ask you about the concept of a quote-unquote "good death." As you know, having a good death is something that has been widely discussed and written about in the bioethics literature for decades. But a good death means different things to different people. But most people see a good death as one that happens at home, surrounded by loved ones. Yet according to CDC data, more than two thirds of all COVID-19 deaths are happening in the inpatient care setting. So, in other words, most people are dying in the hospital, many in the ICU, without the physical presence of family and loved ones. What can health professionals do to help promote some semblance of a good death under these circumstances?

CHAPPLE: So, yes. It's very, very challenging and heartbreaking to contemplate. And it's very, very challenging for the providers because, again, as we mentioned before, they have to be the stand-ins for the family. And so, communication is key. It's possible that if families can't visit, perhaps they can, you mentioned video. There are certainly, they could do a Zoom meeting together or that kind of thing. Family members may be able to get into, or maybe one family member can come, even if they're not allowed into the room. The people who are at the bedside can be given messages for the person who is dying. Phones can be held up to their ears so that if they're unable to be able to see their loved ones on a screen, they can hear their voices. There are those possibilities. Certainly there can be music played in the room where the patient is. If there is a chaplain, I'm sure chaplains also are overworked at this point. But the communication has to be there in terms of what the possibilities are. And the clinicians are responsible for orchestrating the death situation in the clinical setting, especially if, at any time, but especially if the family can't be there. And perhaps they can assure the family that they are in the room when the patient is passing on. That can be very, very comforting to the family if they cannot be there: that they know the person, their loved one, did not die alone.

KAO: Right. No, I think you touched on the role of members of the chaplaincy in hospitals, and they may take on additional responsibilities and ways of ministering that are completely new, given the circumstances.

CHAPPLE: Chaplains are often the ones who are called upon when a patient is near death, but the volume must be enormous for them as well as it is for other clinicians.

KAO: Yeah, and I think that let's hope that, for us who are healthy, continue to physical distance so that we reduce the likelihood of placing individuals and families in those situations. Because it is extremely challenging for all parties concerned, those who are sick, clearly, but as well as those who are working on the front lines: all the members of the health care team, from the doctors, nurses, to the chaplaincy, as you were mentioning. And all the members—

CHAPPLE: Respiratory therapists are not mentioned enough.

KAO: Absolutely. Yeah, absolutely. So, I think we need to give them as much support as we can during these challenging times.

CHAPPLE: Absolutely. Absolutely.

KAO: So, Helen, thank you for sharing your expertise with our audience. But, you know, as a child, I grew up watching a lot of science fiction television shows. So, I can't pass up this opportunity to thank Nurse Chapple on being a guest on *Ethics Talk* today.

CHAPPLE: It's been my pleasure, Audiey.

KAO: Well, thanks again, Helen. For more COVID ethics resources, please visit the *AMA Journal of Ethics* at [JournalofEthics.org](https://www.journalofethics.org). And to our viewing audience out there, live long and prosper. We'll see you next time on *Ethics Talk*. [bright theme music plays]