Episode: *Health By Law: What Should Clinicians and Students Know About the Legal Landscape of Advance Care Planning?*

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[mellow theme music]

[00:00:02] TIM HOFF: Welcome to *Health By Law*, a new series from the *American Medical Association Journal of Ethics*. I'm your host, Tim Hoff. Several actions involving violations of DNR orders—that is, physician's orders to not attempt cardiopulmonary resuscitation on a patient—or violations of patient's advance directives—the instructions about a patient's end-of-life wishes that designate a proxy decision maker—have been brought to courts across the country over the past few years. Other cases involved physician orders for life-sustaining treatments without consent, and still others involved clinicians being charged with battery for implementing DNR orders unilaterally. Among members of the public, these cases tend to tap into fear, anxiety, and a general lack of knowledge about how we and our loved ones should be treated at the end of our lives.

In 2022, the National Partnership for Healthcare and Hospice Innovation collected data about US public attitudes and experiences with aging and advance care planning. [music brightens] Upshots from the data are that most patients don't have their wishes documented, and most have never even talked with a clinician about the kind of care they want to receive at the end of life. Legal support for advance care planning is ethically and clinically important, because it bolsters how well equipped organizations are to express respect for patients' end-of-life wishes and better situates clinicians to guide complex and emotionally fraught conversations with patients and families about death and dying. Joining me today is Dr Thaddeus Pope, professor of law and director of the Health Law Institute at Mitchell Hamline University in St Paul, Minnesota. He's here to discuss what clinicians and students should know about the legal landscape of advance care planning. Dr Pope, thank you so much for being here. [music fades]

DR THADDEUS POPE: Thanks for having me.

[00:01:57] HOFF: The Uniform Law Commission has existed for many years in the US, but since many of our listeners might be unfamiliar with it, let's start there. Why does the ULC exist, and which functions does it serve in US health policy formation?

POPE: Sure. So, the Uniform Law Commission was established back in the 1890s, and the idea was to provide the 56 state legislatures with well-drafted legislation that would bring clarity and stability to critical areas of statutory law, state statutory law. And there's, so there's certain subjects of state law on which it's really important that there's uniformity and consistency from state to state to state. And so, in bioethics or health law, some key examples would be the Uniform Anatomical Gift Act, right? So how can somebody donate organs, right? We have a single national allocation system, UNOS, so it's thought that we should have uniformity in the donation side as well. Or take a recent example. For the past few years, we've been working on the Uniform Determination of Death Act, the UDDA, right? And the idea there is it's sort of intolerable that we would have a patient who could be dead in Illinois but alive in Wisconsin or vice versa, right? Dead is dead. And so, again, the standards for death determination should be the same everywhere. And so, finally, the thought was, well, it should be kind of the same with the Uniform Health-Care Decisions Act. And so, they developed uniform acts for that as well. And they, and a lot of states actually adopted the ULC's Uniform Rights of the Terminally Ill Act back in the '80s. Some more states adopted their Uniform Health-Care Decisions Act in the 1990s. And so, what this is, is sort of an amendment or an update to those earlier uniform acts.

[00:04:04] HOFF: One of the recommendations in this particular update that you're referring to is to reduce barriers to people doing advance care planning. Which factors informed the ULC's formation of this particular recommendation?

POPE: Yeah. So I think there's three big motivators for, as you say, eliminating or reducing barriers. So, the first one is—and all the listeners I'm sure know this—which is there are persistently low rates in terms of how many Americans have done advance care planning or have completed an advance directive. And then secondly, because of that low advance directive completion rate, we see a lot of value-discordant care, right? So people are getting life-sustaining treatment that they probably don't want, right? Because the default is all aggressive, life-prolonging care unless you opt out of it. So, those are sort of well documented problems for a long time. And so, the third key motivating factor is well, we actually have tools now, with technology for example, to eliminate some of the barriers. So, for example, remote witnessing or remote notarization. Sometimes it's hard. We discovered this a lot during the COVID pandemic. It's hard to go out and get a witness or go out and find a notary. Now you don't need to do that because you can do it through Zoom. And then the final thing is, the ULC, what they're trying to do a lot of times is not be super creative, but to kind of summarize and distill best practices that've already been proven out in the field.

[00:05:56] POPE: And so, for decades, the states have been tinkering or calibrating or seesawing between more formalities on the one hand and more accessibility on the other hand. So, for example, many states for a long time required two witnesses to an advance directive. They required the agent that you're appointing to accept their appointment. They required a notary. And those are all good ideas. It helps us have more confidence that this is a valid, an authentic expression of the patient's wishes. But on the flip side, requiring all that extra stuff makes it much more difficult for people to actually get the advance directive done. And so, what the ULC did here was strongly recalibrate the balance in favor of access and ease. So, in other words, making sure that they get done even if they're not, if we're removing some of the security and formality.

[00:06:58] HOFF: Another recommendation is that electronic advance care planning documents need to be widely recognized in statutes, and I imagine some of that has to do with what you're talking about of reducing barriers to access. But why else is this important from a legal standpoint?

POPE: Yeah. So, this, it is related to the access point. I guess it's worth noting a couple of things. First, we've been using electronic documents for a long time, but largely that's been on the clinician side, right? So, for example, many states have a state registry. So EMTs or hospital-based clinicians could access somebody's POLST form or somebody's advance directive and then view it, right? But it's a PDF or it's some other digital document. So what's newer though is that the patient, on the patient side, completes the advance directive electronically in the first place, as opposed to with ink and paper. And Maryland, I think, has been the number one pioneer on that front.

Really notably though, in the new Uniform Health-Care Decisions Act, is that the term is not "electronic document." The term they use is "electronic record." And the significance of that is that it doesn't need to be on paper, but it doesn't even need to be a document at all. So, for example, they note that it could be a video. So you, the patient, you or I or any of the listeners here, could just record themselves saying, "This is who I am, and this is the sorts of health care I would or would not want." And many commentators say that, boy, is that a lot better than a document? Because we could watch you, listen to you, look at your facial expressions and intonations, and we could have more confidence that you had decision making capacity when you recorded that, that it wasn't coerced or under duress. And we actually are more likely to be willing to follow that, right? Because we'll be like, "Well, it sounds like Thad. It sounds like that's what he really wanted," right? Because they can hear it in my own voice. And so, in terms of compliance, people think that a video advance directive might actually be better than a paper document-based advance directive.

[00:09:21] HOFF: Yeah. That's interesting. Are there any concerns going the other way that having this additional media, the ability to look at and hear the person saying these things, might invite unwarranted scrutiny as to whether they really meant it? Are people concerned about that at all?

POPE: Well, the first thing to note—it's a great question—the first thing to note is that already happens, right, with paper advance directives. Because sometimes between the time that the patient is in the ICU and the time that they completed an advance directive years may have passed, and they may have remarried or changed religions or something. But yes, absolutely. Absolutely great question because I accentuated the positive there, and it could actually go the other way. So somebody can take that video and say, "Well, it looks like your grandma there doesn't look like she's 100 percent lucid." So, instead of it reinforcing or bolstering confidence, it could undermine confidence if the patient looks, if she's not speaking clearly, if she's struggling to find her words. So, in which case it gets thrown out because that could never have happened with the paper document, because the words are what they are. But now because of the struggling that she has in uttering it, we're less confident that she really had capacity. So, yes, there are definitely risks as well.

[00:10:47] HOFF: Hmm. That's interesting. Thanks for expanding on that. What does the ULC offer as guidance about when decision-making authority transfers to a designated proxy and which decisions that proxy can make?

POPE: Yeah. So they do two things. In terms of the when question—so, when does the does the proxy take over—everybody agrees that there's no better decision maker for you than you, or there's no better decision maker for me than me. So, almost always advance directives are what's called springing documents, meaning the agent's authority is activated when the principal, or the patient, loses capacity, and the agent's authority evaporates if the patient regains capacity, right? So, so long as you have capacity, you're in charge. Only when you lose capacity does the agent's authority come into being. What the new Uniform Health-Care Decisions Act does is it better clarifies what capacity is to align better with what clinicians have long done, which is they're clearer than lawyers, perhaps, that capacity is decision specific, right? It's not an all-or-nothing thing, right? It's not like Thad has capacity or Thad lacks capacity. The question in the clinical context is, does Thad have capacity to do this? Does Thad have capacity to do that? And so, the new model statute is better about clarifying that—and this is perhaps the most significant example—Thad may lack capacity to make a decision about this surgery, but he might still have enough capacity to decide that he wants so-and-so to be his health care agent.

[00:12:31] In terms of the scope question, we've always held, in all these model statutes, that agents can make health care decisions on behalf of the patient. What the new statute does is it further clarifies that the agent can also request, receive, examine, copy, and consent to accessing medical records. And secondly, the agents are now given authority in the new model statute to apply for public or private health insurance or benefits on behalf of the individual. So, it goes a little bit beyond treatment decisions to allow the agent to do these sorts of ancillary things that might help get the patient health care. At the same time, it also clamps down on the scope of the agent's authority, limiting what they can do in terms of admitting the patient to a mental health institution and limiting their ability to put the patient in a nursing home for long periods of time, except under certain conditions. So, it expands the scope of the agent's authority in some respects, but also constrains the scope of the agent's authority in some other respects.

[00:13:46] HOFF: How does the ULC's recommendation of the recognition of so-called nontraditional relationships relate to this conversation? And why is this equity point also important from a legal perspective?

POPE: Yeah. This is a great, important advance that this new uniform act does. So, you or I could name whoever we want to be our health care agents with the sole exception that it can't be the owner or employee of a nursing home where we are a resident. But again, most of us don't have advance directives. So almost all of the time when patients lose capacity in health care facilities, their legally authorized decision maker is determined not by them themselves, but by what's called the default list, default surrogates. Well, what this new act does is it really materially expands that default list. So, the traditional list would have something like spouse at the top, adult child, adult sibling, and it goes down and down and down through all your blood relatives. Now, just to give a few examples, at the top of the list, it's not just spouse, but right at the top of the list, it's also domestic partner because there are people who you live with and are in a long-term relationship, but you just didn't get married. So, that's right equal with spouse at the top. Also, right near the top of the list is cohabitant, right, which is similar to a domestic partner, but maybe not quite as serious. So these, we recognize, I think, in this new act that many, many people have the person who knows them the best and cares about them the most may not be a spouse, an adult sibling, or an adult child, and so forth, but it may be a domestic partner or a cohabitant. So those categories were added in right near the top of the list. So I think this is really a great advancement that recognizes the way that people live with others in the 2020s.

[00:16:08] HOFF: Clinically and ethically relevant updates to the law can be hard for many to follow due to federal and state jurisdictional differences and state-to-state variations. So, what are your recommendations for how listeners can follow legal updates that affect end-of-life care?

POPE: Yeah, that's.... Well, I think it's worth noting we've been talking about the Uniform Health-Care Decisions Act. No state has yet adopted that. So it's not the law in and of itself. I mean, Nevada, Nebraska, and Delaware have already started to consider adopting it, but it's at this stage like a bill, right? It's a proposal to say, hey, states of the United States, you should consider adopting this. But nobody's actually done it yet. I think clinicians and medical ethicists should generally probably just be concerned about the law where they work, right, the location of care. And I think the best resources, I think, maybe vary from state to state. I think some states, it's going to be the state health care association. So I think California has really good guides on this sort of stuff from the California Medical Association and from the California Hospital Association. Interestingly, in other states like New York, some of the best resources on what's called the Family Health-Care Decisions Act there come from the state Bar Association. So, I think the best resource in your state may vary from state to state. It might be the medical association, it might be the bar association, it might be somebody else. So it's hard to say definitively for everybody listening what the best place for them is to follow advancements. Although one national-level resource that I do think is solid are those that are on the website of the American Bar Association Commission on Law and Aging. [theme music returns] So they collect, at the national level, charts saying these are all the default surrogate statutes, these are all the advance directive statutes, these are all the POLST laws, these are all the. So it's a nice way to get a sense of what's happening at the national level.

[00:18:21] HOFF: Dr Pope, thank you so much for your time today on the podcast, and thanks for sharing your expertise with us.

POPE: Thank you very much for having me.

HOFF: That's all for this episode of *Health By Law*. Thanks to Dr Thaddeus Pope for being here. Music was by the Blue Dot Sessions. For the rest of our podcasts, articles, artwork, and CE opportunities, all available for free, visit our site, journalofethics.org.

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