

Episode: *Ethics Talk — Avoiding Iatrogenic Harm for Dying Patients*

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[mellow theme music]

TIM HOFF: Welcome to *Ethics Talk*, the *American Medical Association Journal of Ethics* podcast on ethics in health and health care. I'm your host, Tim Hoff.

Health professionals generally don't want to talk about iatrogenic harm. When they do, discussion about iatrogenesis tends to focus on problems like adverse medication interactions, nosocomial infections, or surgical errors. Poor end-of-life care likely gets less attention as a source of iatrogenic harm for many reasons, including the fact that it might be harder to identify in the moments when it's happening.

There are a few ways to characterize poor care of dying patients as iatrogenic in nature. Patients can experience overtreatment. That is, they can be subject to aggressive, acute rescue-based care that can extend biological life, but at a great cost to quality of life and quality of dying experiences. Alternatively, patients might experience undertreatment: the underutilization of palliative services delivered to patients with the intention of alleviating suffering, controlling systems that exacerbate suffering, and prioritizing quality of life and quality-of-dying experiences. Inpatient or in-home hospice, for example, includes dramatically underutilized federally funded services for dying patients in the U.S. And more generally, iatrogenic harm in end-of-life care can take the form of failing to have difficult, complex discussions between clinicians, patients, and their loved ones that could clarify when and how to transition from rescue-based care to comfort-based care.

Examining end-of-life care as a site of potential iatrogenic harm is critical for ensuring healthy dying, as well as addressing concerns about the ways that marginalized patients receive inequitable care throughout their lives. Joining us to discuss is Dr Helen Chapple, a Professor at Creighton University in Omaha, Nebraska, whose extensive bedside nursing experience includes home hospice, research, and critical care. Dr Chapple, thank you so much for being on the show today. [music fades]

DR HELEN CHAPPLE: Thanks so much for having me.

HOFF: Poor care for the dying can be hard to spot for a number of reasons, one of the main being that very few people, including many clinicians, are familiar with what good care of dying patients looks like. So, how can the concept of healthy dying help us to recognize poor care for dying patients as a form of iatrogenic harm?

CHAPPLE: It's interesting that iatrogenic has a number of different valences to it, and one of them is that it's sort of direct. You can sort of trace the harm back to a particular cause.

HOFF: Mmhmm.

CHAPPLE: But I think that poor care of the dying would require us to think about the condition of dying as an identifiable, something separate and apart from rescue or from a

no code, for instance. My feeling, though, is that on acute care units, the care is pretty dualistic. You're either on the train that puts you onto rescue, sort of getting everything, or you're someone with a DNR order, which puts you into sort of a more complicated treatment plan. So, clinicians have to ask themselves, are we going to do this now that they're a DNR, or how much of it do we do? This dualism between the rescue, sort of being on the rescue train and not being on it, is mostly due, I believe, to clinicians' perception that they need to make decisions very rapidly about the plan of care and implement those decisions right away. So, it's a patient management problem. Patients in the rescue basket don't require the team to face or respond or think about existential questions so much. Everyone seems to understand the plan pretty implicitly: We're trying to rescue them.

HOFF: Mmhmm.

CHAPPLE: The patients in the second basket, the no code basket, are going to be harder to manage. But fortunately, their number is much lower, and they may be transferred to a less acute care area fairly quickly. So, the complexities of a mixed plan of care that matches the patient's true condition of dying without iatrogenic harm, it rarely comes up.

I want to also point out that there aren't very many facilities that place a priority on paying attention to how good the care was for a patient who died, what went into that care. The mechanisms for meaningful follow-up after a patient dies are just really not in place most of the time. We would do M&M rounds, for instance, perhaps, but rarely on a patient who just dies, right?

HOFF: Mmhmm.

CHAPPLE: Unless we need to figure out that we think there was actual iatrogenic harm about the rescue. We don't fill out code sheets to track trends in practice. It's really easy to find prescriptions for how to care well for dying patients, but we don't follow it up. And following up and tracking is something that we don't do, and we really do track the things that we care about. So, I think we can notice that if we're not tracking dying patients in terms of how well they died, then we can infer that it's a low priority. And I'm not saying, though, that clinicians don't care about how patients die. Of course, they really do.

HOFF: Mmhmm.

CHAPPLE: What I am saying, though, is that the culture of acute care and its structures don't support paying attention to it in a very meaningful way.

HOFF: Hmm. Earlier, you said for patients who are placed in the "rescue basket," the clinicians are not incentivized really to approach the existential questions that might come along with sort of, I guess, facing dying. Can you expand a little bit on what those questions are? Since even knowing what they are before you approach them might be helpful in answering them in a productive way.

CHAPPLE: So, this is where I think moral distress comes in for nurses, because they notice perhaps that patients aren't responding in a way that a recovering patient is going to respond.

HOFF: Mmhmm.

CHAPPLE: And they will be asking questions about, well, maybe this patient should be no code. Should we be doing all of these things for this patient? Is the family prepared for the fact that we can see, we can predict that this patient is going not to survive?

HOFF: Mmhmm.

CHAPPLE: How are we communicating with the family? How are we communicating with the patient if they're still able to communicate? So, those are some of the questions I think that people who are actually administering the care and carrying out the orders often have, but they may not know how to bring them up.

HOFF: Because of attitudes and education about death and end-of-life care, dying patients are at risk of receiving less attention and fewer resources than they deserve, especially, as you say, if they're not given this sort of rescue treatment, as in other areas of health care where there's a "underclass" of patients, patients of color within that class tend to receive even worse care. So, what do we know about how patients of color are treated equitably or inequitably, for example, at life's end?

CHAPPLE: So, as you might expect, when we think about patients of color, the issues are more complicated. In the first place, we know that the stress of enduring microaggressions and racist policies constitute what we call an allostatic load for patients of color that exacerbates their conditions. And that load is not something that white patients share. So, also, we know that universal access is not a fact of life in the United States, so that when Black patients present with serious illness symptoms, they're often sicker, and they're presenting later in their illness than White people.

HOFF: Mmhmm.

CHAPPLE: At the same time, we can't necessarily assume that Black patients are open to limiting treatment. So, Annette Dula and September Williams have written for us that living longer is often a victory for patients of color.

HOFF: Hmm.

CHAPPLE: Why should Black patients and families be reluctant to partake of the high-end rescue care that's being offered to them now when the preventive measures that they needed earlier on were not being offered to them?

HOFF: Mmhmm.

CHAPPLE: So, part of the puzzle here is to communicate frequently, not just informing patients, but listening to discover goals, to discover meaning as the patient's condition shifts.

HOFF: Mmhmm.

CHAPPLE: There's a bunch of research out there that shows that frequent meetings with families over the course of a patient's time in that unit works better than just having a meeting at a critical point far down the road.

HOFF: Mmhmm. That makes sense. That sort of leads well into this next question about cases in which distrust between patients and clinicians can lead to overtreatment. So, for

example, a Black patient receiving palliative end-of-life care might be aware of the pervasive undertreatment of pain among Black patients and then feel an intense need to advocate either for themselves or for their loved ones quite aggressively, ultimately resulting in overtreatment. Undertreatment on the other hand, could certainly be considered a source of inequity, particularly when it comes to comfort care and symptom management, and failure to help patients understand what constitutes good end-of-life care in terms of symptom control could result in some patients of color getting overtreated in terms of aggressive, acute rescue-based care when they should be getting high quality symptom management during experiences of dying. When we were trying to develop a question kind of in this realm, we found that the clinical literature on equity in end-of-life care doesn't really have much specifically on this topic, but folks in the clinical realm report this kind of thing pretty frequently. So, the question is, what are the key knowledge gaps about end-of-life care equity that researchers should be seeking to fill to avoid this kind of iatrogenic harm to dying patients of color?

CHAPPLE: Well, to a certain extent, you're actually answering the question yourself by noticing that symptom management among people of color is much worse than it is for White patients. And that alone is not very well known among clinicians. The implicit bias that clinicians have in the way that they treat, they fail to teach, they fail to do symptom control, they fail to understand the difficulty, perhaps, that families have showing up, getting transportation, being responsive. These kinds of things are not clear necessarily to clinicians. So, education is always a good start. hBut I would also like to point out that high quality symptom management should be available to all patients with serious illness all the time that they are in the units. We tend to make it a second thought or a third-line thought.

HOFF: Mmhmm.

CHAPPLE: Palliative care teaches us that symptom control is possible at all stages of serious illness. So, it's this sort of dualistic patient management problem that I mentioned earlier. It has influence here as well. So, we tend to offer aggressive attention to symptoms only when we're no longer thinking about rescuing the patient from death.

HOFF: Right. So, in some instances, clinicians might not be aware of certain influences on their own delivery of care like you're talking about with an implicit bias. The clinical literature demonstrates how prevalent it is, regardless of whether or not the individual clinicians are aware of it. But going the other way, how should clinicians contextualize and understand the patterns that they see as common in clinical experiences that they don't see borne out in the clinical literature yet?

CHAPPLE: So, I think that you have to go towards what the questions are that you know are big questions and do come out in the literature, like the fact that we know that people of color are not getting good symptom management. Then you can put it together with, like I said, what palliative care is telling us and then to wonder, well, okay, why? What is it about critical care that keeps us from looking at symptom management?

HOFF: Mmhmm.

CHAPPLE: And we know that these patterns of care are basically culture related. They are structurally related rather than individual related.

HOFF: Mmhmm.

CHAPPLE: Although, I would say that implicit bias is definitely an individual problem, it's just also baked into the way that we work.

HOFF: Mmhmm. Mmhmm. So, in response to that, at which levels are interventions required to ensure care equity for all dying patients? As you've mentioned that we need, obviously, education on these things, so is it a matter of just getting more end-of-life care curricula into health professions education? Is it more resources for underfunded care facilities with not enough staff to care well for all their patients? Is it some other systems-level change at the level of policy and governance? Walk us through a little bit of the different levels here.

CHAPPLE: So, education is always a good idea. It's always a good first step.

HOFF: Mmhmm.

CHAPPLE: But it doesn't often change behavior.

HOFF: Mm.

CHAPPLE: So, when we talk about ethics questions, we can say, oh, golly, if people just knew the right thing to do, then they'd do it.

HOFF: [chuckles]

CHAPPLE: But we know that that's not the way things work.

HOFF: Right.

CHAPPLE: So, in fact, one of the system-level kinds of things we need to notice is what I said earlier, that we track what we care about.

HOFF: Mmhmm.

CHAPPLE: We incentivize. It's what do we incentivize? The incentives for ongoing interventions are enormously powerful, enormously powerful. Because rescue interventions involve monitors and devices and pharmaceuticals, and all those things are tied to good business, right? To capitalistic goals.

HOFF: Mmhmm.

CHAPPLE: And there is, I cannot emphasize enough how powerful those influences are, but we don't see them. They're way, way, way behind the scenes.

HOFF: Mmhmm.

CHAPPLE: And so, we don't even, so, we don't think about the fact that we are not tracking how well our patients are dying, first of all, and what goes into making one patient's dying experience better than another's?

HOFF: Mmhmm.

CHAPPLE: Where are the, what are the things we are striving to achieve, and how do we know whether we're meeting our goals? These questions are often not asked at all in an acute care environment. We will go to families of patients who died, and we may ask them how the experience was for them. But we're not looking at it from a clinical standpoint. We're not going back and asking questions about, well, how did this patient die? Who took care of them? What kinds of things were being done? We don't do that often.

HOFF: So, can you elaborate a little bit on that last sentence about what else we can track that's not in line with sort of current incentives? What sort of things would we be looking at outside of, like you say, patient family surveys and things like that?

CHAPPLE: We might be looking at how much symptom control did they get? What were their symptoms? How consistently were they treated? What kinds of drugs did they receive? If we withdrew life support, how long was it between the time that we withdrew life support, and how did we withdraw life support? Was it, did we take the pressers off first? Did we take the, did we extubate the patient? How did they react? What kinds of drugs did they receive? Was the family at the bedside? How were they interacted with? Those kinds of things would be wonderful to know, to track, as deaths occur.

HOFF: Mmhmm.

CHAPPLE: Deaths can occur much more often than we might know, and the hospital certainly tracks that because they have to. But the nature of the dying process is not recorded anywhere, often. Sometimes even the amounts of drugs are given on a PRN basis by the nurse, and they may or may not be charted fully.

HOFF: Mm, sure.

CHAPPLE: And they may not be, the symptoms that were being controlled by those drugs may not be charted either.

HOFF: Mmhmm. To wrap up, hospice underutilization suggests that current health professions students and trainees are more likely than ever to need to know how to care for patients at the end of life. So, what should they know about their roles in ensuring good end-of-life care for their patients? Which, obviously, every patient will need eventually, even if these particular students and trainees are not going into hospice or not going, you know, not focusing on palliative care.

CHAPPLE: Sure. So, the communication that I mentioned and having frequent meetings with the families and talking about goals, those kinds of opportunities for interaction are critically important. But there are some also practical things that it would be helpful for all health care professionals to know. One is that the hospice benefit is an entitlement for every single person on Medicare, something that most people don't know. There is this sense that the six months is arbitrary, and it's pretty difficult to apply, as we know. And they may or may not know about the surprise question, which Joanne Lynn has told us is a better question to ask. "Would I be surprised if this patient were to die in six months?" Not, "Do they have six months to live?"

HOFF: Hmm, mmhmm.

CHAPPLE: Among older people, weakness, increasing weakness and weight loss are two signs that they are nearing the end of life.

HOFF: Mm.

CHAPPLE: So, it's a handy thing just to know if you're dealing with people who are quite elderly and becoming more frail. So, it's a signal we need to be talking about goals with these patients. Living wills are pretty useless among, especially way ahead of time. If you don't know, don't have any idea in the world how it is that you're going to die, I don't know that a living will is that helpful.

HOFF: Mmhmm.

CHAPPLE: But in the setting of a serious illness, what we're calling now serious illness conversations, do make sense in terms of the variables have narrowed. Now we have some idea of how dying might occur for you because we know what might kill you because of the disease that you are now struggling with. And conversations among family members can be about what a person might want, can be rehearsals for the chaos of this unwelcomeness that will certainly come someday. And I think it's also important for people to recognize that the state of dying is not something to wipe out or to be so completely—mm, what can I say—taboo.

HOFF: Mm, mmhmm.

CHAPPLE: That state of dying is really an opportunity for making meaning and for kinds of family interaction that doesn't happen in any other time of your life. It just can't.

HOFF: Hmm.

CHAPPLE: So, that I think it's important for people to take another look at the state of dying, not as something that we should skip over, but as a way of.... And it's an adversity, of course, but living through it among the people that you love can create meaning and create memories that are tremendously important for the survivors going forward, especially. [mellow music returns]

HOFF: Dr Chapple, thank you so much for being on the podcast with me this month and for your ongoing work with the Journal.

CHAPPLE: Certainly. It's been a pleasure, Tim.

HOFF: That's our episode for this month. Thanks to Dr Helen Chapple for joining us. Music was by the Blue Dot Sessions. To read the full issue for free, find more podcasts, art, CE opportunities, and more, visit our site, JournalofEthics.org. For all of our latest news and updates, follow us on [Twitter](#) and [Facebook @JournalOfEthics](#), and be sure to check out our new series of author interviews. And if you're listening on Apple Podcasts, please take a minute to rate and review the show. It'll help get our episodes to more folks interested in ethics in health and health care. We'll be back next month with an episode on low-wage health care work and the people who do it. Talk to you then.