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Session 5: Medical Futility: Institutional and Legislative Initiatives

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CHAIRMAN PELLEGRINO: Our next speaker on the subject of medical futility, institutional and legislative initiatives is Thaddeus Pope, lawyer and philosopher, J.D. , Ph. D., associate professor of law at Widener University Law School . Dr. Pope ?

DR. POPE: Good morning. It's quite a privilege to be invited here to address this quite distinguished body and to be among the other quite distinguished speakers. Thank you for inviting me to speak, and it's nice to be back just a few hundred yards where I started the systematic study of ethics, in fact, as a teaching assistant for Prof. Gómez-Lobo.

I cut a few slides out. So on the hard copies that you have, you might have to skip ahead at just a couple of points. I want to proceed in just six steps. I want to first illustrate and define a futility dispute and then, second, identify the causes of futility disputes, and, third, while most are resolved through consensus, there is a significant and growing and subset of disputes that remain intractable. And the focus of my remarks is on those intractable disputes.

Fourth, in response to the intractable disputes, professional medical associations and individual institutions have developed policies on when providers could refuse treatment, but those policies lacked legal backing.

So fifth, many states passed statutes to give that backing, but those statutes were not well drafted and failed to provide safe harbor protection. So across the United States providers are legally chilled from practicing the medicine that they consider appropriate.

And finally, sixth, the one major exception to that is Texas .

So what's a futility dispute? And this is probably superfluous, but just to frame and orient things, this is a relatively high media profile case from Texas . Emilio Lee Gonzales was born generally healthy, but when he was about one year old Emilio was diagnosed with Leigh 's disease, a neuron metabolic disorder that affects the nervous system.

In December 2006 Emilio was admitted to the PICU at Children's Hospital of Austin , where his neurological status continued to worsen as his brain atrophied. He was dependent upon a mechanical ventilator, nasojejunal tube. He was semicomatose. He could not empty his bladder. He was having frequent seizures, and providers had great difficulty keeping his lungs inflated.

Emilio's heath care providers determined that his condition was irreversible and that the continued treatment “would only serve to prolong his suffering without the possibility of cure.” They felt that “the burdens associated with his current care plan outweigh any benefit Emilio might have been receiving” and that “his aggressive treatment plan amounted to a nearly constant assault on Emilio's fundamental human dignity.” But Emilio's mother,

Catarina, refused to consent to the withdrawal of life-sustaining treatment. She insisted that Emilio's provider sustain him until Jesus takes him. During the winter of 2007 the care team and Catarina had multiple conferences to discuss his condition and his treatment plan, but they could not reach any consensus.

This is a futility dispute where the patient, whether herself or, more often, through an advance directive or through some form of substitute decision maker, wants to continue aggressive life-sustaining medical treatment. But the provider, on the other hand, thinks that that is inappropriate and does not want to give it. Now, that model presumes a certain unity among surrogates and a certain unity among providers. And, of course, certainly two daughters may disagree or two physicians may disagree, but the paradigm futility dispute is between the surrogate on the one hand and the provider on the other hand, and that's what I'm going to focus on.

I'm not going to address macro issues about how Medicare should make coverage determinations. I'll leave that to the Congressional Budget Office and ARC. In last month's archives, a surgery survey showed that 44.3 percent of physicians- — of professionals — thought that patients have the right to demand care that their doctors think will not help. Many argue that that figure — 44 percent — is too high and that more physicians should cancel their subscription to the technological imperative.

I'm not focusing — let's go back to the same survey. I'm not focusing on whether physicians give too much inappropriate care. I'm focusing on the spread here. There are many more patients and surrogates who think that they have a right to demand inappropriate care than there are physicians who think that they have that right. And just another question from the same survey. Even where doctors believe there is not hope of recovery, 21 percent of people think that all efforts should continue indefinitely.

So to understand the causes of conflict we have to look at both the reasons surrogates insist on continued life-sustaining treatment and the reason that providers resist those demands. Religion is a big one. In many intractable disputes, including some of the most famous — Baby K and Emilio Gonzales — surrogates request continued treatment because it's called for in their religious or cultural tradition. Only God can give and take life. Another survey showed that a lot of people, 60 percent, believe in miracles, believe in divine intervention.

In addition to religion, in this study in *Critical Care Medicine* nearly 90 percent of participants expressed doubt in physicians' ability to prognosticate. With greater access to the information — on the Internet, for example — people have a greater awareness of uncertainty in medicine, and they're more confident in opposing health care providers. There's a substantial body of evidence that shows African Americans are more likely to request unconditional prolongation of life-sustaining medical treatment, less likely to agree with the health care recommendation to stop.

And today, where the incentives of managed care are well known, even non-minorities are distrustful. Grief, guilt, family dynamics, some of the other reasons that Prof. Emanuel had referred to. And it's easy for surrogates to act on all these reasons because the costs of their decisions are externalized largely to the payers and to the nursing staff.

Now, conflict requires two parties, so here it's not just that surrogates are more likely to insist on continued treatment, but it's also increasingly likely that providers will resist. And a key reason is they want to prevent a patient's suffering. They want to-- — and Prof. Curlin really got into this yesterday — they want to preserve the integrity of the medical profession. They also want to prevent moral distress. Providing futile care is the highest and most significant source of moral distress among nurses. Providers want to be good stewards of health care resources.

And finally, providers want to honor patient wishes. Most futility disputes are between a provider and a surrogate, not the patient him or herself. But surrogates are often wrong about what patients would want. Therefore, to resist the surrogate's decision may actually promote, not thwart, the patient's preferences and the patient's interests. So that's the causes.

Now, the good news is that most futility disputes are resolved informally through good communication and mediation. Consensus is reached more than 90 percent of the time, but there's this core subset of disputes that remain intractable. In this study [referencing slide] four percent, two percent, seven percent, two percent. Now this range, this rate of intractability, will probably decrease, will probably shrink with better end-of-life communication, but it won't be eliminated. So there's always this range- — even though we can achieve consensus most of the time, there's always this subset of intractable disputes.

So professional medical associations and individual institutions developed policies to address how to resolve the intractable disputes. And there's a whole bunch of them, but obviously for the sake of time I have to focus on just one, and I'll focus, as Prof. Emanuel , on the AMA's. A little over ten years ago the AMA recommended that all health care facilities adopt a futility policy, and it promulgated for them a model policy, a seven-step approach. The first five of seven steps were all directed at what lawyers refer to as internal dispute resolution, trying to resolve things informally and internally using deliberation, negotiation, communication. And if the care team can't do it themselves, then in Step 3 you bring in the assistance of consultants, bioethics mediators, social workers. If that doesn't work, even Step 4: use the ethics committee.

But in the intractable disputes, none of the first four steps work, and so you go to Step 6: try to transfer the patient to another institution that is willing to provide the requested treatment. If you can't find a willing provider — and you usually cannot, so this is a big contrast to the discussion yesterday in the contraceptive situation where you can usually find somebody else; here, you usually can't make a transfer. Then, the AMA writes, the intervention need not be offered. So for these two percent, four percent, seven percent of intractable cases that can't be resolved with internal mechanisms, the AMA says the provider can just refuse.

But — the very next line — the AMA writes that legal ramifications of this course of action are uncertain. And indeed, by the 1990s many damages had been paid in cases that had been litigated. Now, based on the outcomes of several particularly well-publicized cases and a big pile of medical journal articles, commentators conclude that the courts have almost universally sided with the family and against health care providers. In fact, when you look at the body of litigated cases, providers have won the overwhelming majority of litigated futility cases. But the salience of the reported cases combined with misinformation created a perception of broad liability exposure. Plus, providers aren't just liability averse; they're litigation averse.

This perceived legal risk had a material impact on provider behavior. In 1996 a group of researchers at St. Louis University — “SLU," as they refer to it — surveyed 2,000 large hospitals in the United States . Of 537 respondents, only 29 had futility policies. Moreover, most of these 29 envisioned primarily a consensus-building approach. So almost none included the AMA's seventh step.

So providers give in. They don't want to, but they do. In 1976, providers were reluctant to withdraw life-sustaining treatment with consent, with the authorized consent, because they didn't have clear legal authorization. Today they're reluctant to withdraw treatment without consent because they lack clear legal authorization for that.

So by the early 1990s protection was on its way, the legal protection that they wanted. Many states enacted statutory safe harbors, which basically — and this is pretty accurate. They basically tell the provider, “Look, if the surrogate is asking you to do something — aggressive life-sustaining treatment that you feel is inappropriate professionally — you don't have to do it. If you can't transfer the patient, you may unilaterally stop, and you have civil, criminal, and disciplinary immunity from doing so.”

At least ten states have very similar statutes because they adopted their statutes all based off the Uniform Health Care Decisions Act. And that act — this is New Mexico, which I'm using because I was just there, which basically — and this is true of most state laws, not just the uniform health care — that basically say the general rule is you, the provider, you should

comply with decisions made by the patient or made on the patient's behalf. But there's an exception: except as provided in Sections E and F. So in F — I'll just read it. “A health care provider or health care institution may decline to comply with an individual instruction or health care decision that requires medically ineffective health care or health care contrary to generally accepted health care standards.”

And, importantly, if you're going to use that exception, you're not subject to civil or criminal liability or to discipline for unprofessional conduct. So it seems to be just what providers were looking for. But the safe harbors proved to be illusory. They have for the most part failed. Providers continue to accede to surrogate demands. They are chilled from doing what they want to do. Health care providers are very litigation averse, so in order to work, safe harbors have to be clear and precise so providers know what they need to do to be protected.

The safe harbors here, in contrast to, for example, peer-review safe harbors, are neither clear nor precise. The key language here is quite vague. What is a “generally accepted health care standard”? What is a “significant benefit”? Worse, this language basically folds into a malpractice standard, which means providers need not give care that is outside the standard of care. But since the care is provided and has been provided, providers are continuing to create the very standard of care from which they want to escape.

Vagueness means uncertainty, and uncertainty means no futility policies are written. And if they are written they're not used up to the point of the seventh step. Now, we can't fault the state legislatures too much because this vagueness — and we heard this earlier from Prof. Emanuel-- — the vagueness was unavoidable. We can't agree. We have no consensus on what the standards of medical inappropriateness are. Maybe with these tiny exceptions — a brain death, although that may be collapsing as we speak, anencephaly and physiological futility. But even there, even with brain death, for example, we continue to have litigation, or threaten litigation, to keep dead patients on life support.

We can't agree on a quantitative standard, and we can't agree on a qualitative standard. And as we heard yesterday, we basically cannot agree on the very goals and ends of medicine itself. Is the mere prolongation of corporeal existence a goal of medicine? Therefore, we've basically arrived at the point where we've determined that futility must be identified as Justice Potter Stewart identifies pornography: “I know it when I see it.”

So in the intractable cases, providers cave in. Right? And do what the surrogate wants. And this may seem like a small circle, and maybe we should say, “Well, it's such a small circle. What's the harm?” Well, it's growing. Surrogates are increasingly likely to make demands that their providers determine are inappropriate. When we ask people, “Should we do everything to save a life?” fifteen percent said yes in 1990; 22 percent in 2005. Same thing from other studies. People are more likely to demand inappropriate care. Plus there are more and more elderly patients, and there's more and more technology available to sustain them. And again at the same time, on the other side of the equation again, providers are increasingly likely to resist these demands. They're more willing to stand up for what they believe is professionally appropriate.

So more surrogate insistence combined with more provider resistance leads to more intractability. So that's the general situation in the United States . And what I want to do is just note two exceptions to this general cave-in rule, and then I want to finish by describing how things work in Texas .

First exception is that if the provider thinks that the surrogate's request is inappropriate — really inappropriate — then maybe that person shouldn't be the surrogate. Now, famously in the Wanglie case, which was mentioned earlier, the patient's proxy would not consent to stopping life-sustaining medical treatment, which was the recommendation of Hennepin County Medical Center . So the providers petitioned the local probate court to appoint a professional conservator to make decisions on behalf of the patient instead of the person who was. But the probate court denied. Right? Because the current decision maker was the husband of 53 years and the probate court said, “He's a fine decision maker. I'm not going to replace him.”

But more recently courts have been more willing to replace surrogates. In one Boston case the court replaced — and there's a lot of Boston cases. The court replaced an agent because he was in denial about the deterioration in his mother. He did not give full consideration to acceptable medical alternatives.

And just a few weeks ago, a New York court replaced a daughter who was the — not only was she the daughter, but she was appointed in the advance directive as the agent — replaced her because she failed to appreciate her mother's true medical needs and lacked the objectivity to make the necessary decisions. So that's — if you don't like what the surrogate is asking you to do, find a new surrogate.

Second exception to the sort of general cave-in rule in the United States is that because providers perceive little legal authorization to resist surrogates openly, many do so clandestinely. Surveys indicate that many withhold or withdraw life-sustaining medical treatment without the knowledge of the patient or surrogate. And so this is a lot like the early 1980s where we had — the New York cases where we had the purple dots, where we indicated who was going to be DNR status. We didn't have DNR orders but that's the way we did it, and then take the purple dot off afterwards. And, of course, these things still persist even today: show codes, slow codes, Hollywood codes — secret, masked withdrawal and refusal of inappropriate treatment. Obviously very dangerous, but it's certainly happening.

Now obviously I'm painting with a really broad brush. I'm describing 49 different states altogether in one fell swoop, but the differences between and among those 49 states and DC pale in comparison to any of those in Texas. Texas providers recognized the vagueness problems in other states' safe harbors, so they abandoned any effort to define the circumstances under which treatment could be refused. Instead they defined a safe harbor — defined and earned solely by the satisfaction of procedures.

Texas 's act, the Texas Advance Directives Act, grants total and complete deference to the treating physician as long as the physician's recommendation is confirmed by an ethics committee. The surrogate is given 48 hours' notice of the ethics committee. The surrogate is given the committee's written decision, and the surrogate is given ten days to try to transfer the patient to another facility, assuming the ethics committee has decided that that facility is not going to give the treatment. Now, there's a section, 166.046, that defines those procedures that must be satisfied. And in the immediate prior section, 166.045 says if you use 166.046 you are not civilly, criminally liable or subject to review or disciplinary action. There's no substantive standards. It says all you have to is comply with the procedures and you're safe.

So in contrast to the approach in all the other states, the Texas act makes no reference to health care standards, only to procedures: 48 hours, meeting, decision, ten days. Right? These are concrete. They are measurable. Providers know when they've earned safe harbor protection. So let me just quickly illustrate this in operation, as used in the Gonzales case. So there's Emilio Gonzales . They had — the treatment team thinks it's causing suffering and there's all these patient care conferences, but the mother remains adamant. So the hospital invokes step one of the formal process. They give Catarina this letter telling her there's going to be an ethics committee meeting. The ethics committee has its meeting. Catarina attends. The committee decides to support the physician. It agreed that the suffering outweighed any benefit. The result of the ethics committee is usually agreement with the physician.

The decision of the ethics committee is memorialized into a written decision. That's handed to Catarina. And at this point, upon the service of the ethics committee decision, Catarina — the ten-day clock starts to run. So she has ten days to look for a transfer, some place that's willing to give the treatment that Children's Hospital of Austin is unwilling to give.

Usually the ten days comes and goes and families are unable to find a transfer facility. When that happens, on the eleventh day the treating facility can withdraw the life-sustaining treatment, and there's no other recourse for the surrogate. The Health Care Ethics Committee decision is final. You cannot go to court to question the ethics committee. The Texas mechanism has been involved thousands of times, often even in the face of intense negative

press coverage.

The Texas statute is perceived as a success by the provider communities. Studies show that the Texas statute improves the rate of the informal resolution, the first five steps of the AMA process. Intractable disputes, when they are intractable, they get decided in favor of providers. And the health care ethics committees don't always — it's not a hundred percent. It's more like 80 to 90 percent. They don't always agree with the providers, so it looks like they are weeding out. The cases we're stopping is now truly inappropriate. For these reasons it's perceived as a success, and other states — including other countries — are looking to Texas as copying its statute.

Now, I just want to say a couple of things about Texas . This has all been descriptive, but this is a little bit of tiny normative point right at the end. Where you have fundamental and irreconcilable values the best you can hope for is process, but if process is all you have it has to be fair both for public trust but also it affects the very validity of the law.

In its current form, it's extremely unlikely the Texas statute will last another six months. First, it doesn't comport with the requirements of Constitutional procedural due process. Forty-eight hours' notice for the final life-and-death decision is too short, and the ethics committee is not sufficiently neutral. Apart from judicial challenges, it's likely that the legislation will either be amended or repealed in the last regular session of the Texas legislature in 2009. It almost happened in 2007, where they were at least going to make these changes.

A process-based approach may be the way to go, but we have to attend to procedural fairness. They've been around for 30 years, but health care ethics committees are not ready. They don't have the competence, they don't have the neutrality to exercise the sort of decision-making authority that the Texas statute has given them.

Thanks.

CHAIRMAN PELLEGRINO: Thank you very much, Dr. Pope . Prof. Peter Lawler has consented to open the discussion.

PROF. LAWLER: Thanks so much for a fabulous presentation. I learned a lot. I'm not a physician. I'm a mere political scientist. So — still a doctor, though. And there is a principle of political science here that you're calling attention to, and that is procedure can simply be a way of resolving a fundamental dispute when it comes to substance. When fundamental values disagree, it's still possible to have a process-based resolution. But in political science we say there are really definite limits to that. There can be some disagreement but not too much. So the Americans disagree on a lot of things, but the Americans have to agree on limiting government, freedom of religion, and all these things. So there has to be a whole lot of substantive agreement before you can turn it to process.

Too much substantive agreement can't be solved by process alone. And you've been telling us, as a lot of the other speakers we have had have been telling us, the medical profession is plagued by a lack of consensus and, in fact, an increasing lack of consensus. At the end of your fine article you say we don't have any consensus on the proper ends of medicine. And we heard yesterday this is getting worse. We no longer know what health is, and we're no longer even sure health is in the area of enhancement and catering to the patient's needs and so forth.

We no longer even know whether health, strictly speaking, is the end of medicine. So, A, we don't know what health is, and if we did know what health is we wouldn't be so sure health is the end of medicine. And your second point is we may have to ration medical care. We already are in some ways. But we have no consensus on the acceptable criteria for rationing. So can process really resolve that?

And we somehow know there should be legitimate restrictions, number three, on patient autonomy, and providers really want there to be restrictions on patient autonomy because, to

speak plainly, sometimes providers think that patients are nuts, causing cruel and unusual suffering for no good reason. But we have no clear criteria for those limitations.

And not only that, you told us the situation is getting worse. The patients are getting more insistent that everything be done. The providers are getting more resistant. So you have kind of a culture war between patients and providers. And then you have this very word *futility*. We have no idea what that means, so we have this futile quest to define *futility* . Gil Meilaender said in the last session it's very questionable what *futility* means in this sense. Someone might says this: “It's never futile to sustain human life. In fact, it's a sign of emotional maturity to get over your personal suffering, your personal squeamishness, and go ahead to affirm the infinite value of the life before you by sustaining it.” But others would say it's very immature to sustain life that ain't never going to come back, that's always going to be unconscious. But then Gil might respond, “Futile becomes a little blurry the more you think about that because it might come back a little, or there might be a small chance it will come back.”

So with all this in mind and even real, radical disagreements about what existential maturity means and what cultural growth means, because you say even in your article that this consensus is not imminently forthcoming. That may be deep irony. Or you may agree with the presentation this morning that as cultural growth really starts to kick in these consensuses we're looking for will forth come. But I doubt it. I tend to think that the situation — as medicine gets more powerful, as Leon Kass well said, the purposes of medicine are going to get more blurry, as we've seen so many examples of the last day or two.

So I'm little bit doubtful that process can simply resolve all this, and *process* seems to me to mean, in the final analysis the physician in 80 or 90 percent of the cases backed up by the ethics committee, his view of futility or her view of futility and appropriateness is what triumphs. I forgot this was *Jeopardy* . I haven't put this in the form of a question, but let me just say a little bit more to show me that process can really overcome this problem of not only incompatible values, but values get more incompatible all the time.

CHAIRMAN PELLEGRINO: Thank you, Peter . Dr. Pope responds, and then we'll return to the Council for further comment.

DR. POPE: I'm not sure that I agree that there's a limit to what process — I mean, I'd be real interested to see that literature that suggests that when substantive agreement reaches a critical point that process —

PROF. LAWLER: For example, there are limits to toleration. You can't tolerate people who don't accept your fundamental principles. So Democrats and Republicans can have process-based solutions. Democrats, Republicans, communists, and fascists, and throne and altar monarchists, there probably can't be a process-based resolution to all their differences.

DR. POPE: Maybe we're not on the same page, because maybe when you say “process-based,” the object of the process — maybe what you're thinking is consensus, while the outcome of the process here is certainly not consensus. It's like the court system. It's process-based. We don't have *ex ante* standards that tell us the answers to lots of different sorts of disputes, but we're reasonably happy with the process.

And so I guess I think that a process-based approach is inevitable. The real question is really what the form of the process is. Are we going to create — are we going to empower ethics committees, or are we going to retreat from where we went to in the 1970s and send end-of-life disputes to the courts? We didn't think that was a good idea because we thought courts don't have the competence. They're too slow or they're too expensive. But maybe we trust courts. That's a process-based dispute resolution mechanism that's been around.

But I agree that given a lot of the points that you mentioned that it doesn't look real promising. In fact, for that reason it looks like this discussion about how providers and patients should resolve these sorts of disputes will probably in a temporal context be overtaken by the payers. In other words, since we are so slow — and you're right that the

disputes are so intractable and growing in their ferocity that it's going to take us time to work that out. In the meantime, when Medicare starts to consume 90 to 100 percent of the entire federal budget, decisions will be made. So things may just end up being resolved that way.

CHAIRMAN PELLEGRINO: Thank you very much, Dr. Pope . Dr. Meilaender ?

DR. MEILAENDER: I'd like to make — these aren't really questions. They're two comments, and they may seem perverse. You may make of them what you will. But I start by saying that I don't actually for a moment think — it's not that I think doctors must do whatever patients want. I don't think that at all. But I just want to note a couple of things that are puzzling to me.

You described — I don't have the exact thing, but I scrawled it down. When you were describing the notion of a safe harbor, it was that I'm asking you to do something that you think is inappropriate professionally. You don't have to do it, and we provide you with a safe harbor that protects you in that decision.

The strange thing to me — and I don't quite know what's going on — is that in our discussion yesterday about a different set of issues in reproductive medicine, the pressure seemed to be that if I ask you to do something that you think is inappropriate you should do it anyway. And now in the end-of-life decisions the pressure seems to be that when I ask you to do something you think is inappropriate you don't have to do it.

Now maybe there's an explanation to work that all out, but I think there's more going on here than has come to the surface and that there are, in fact, buried judgments about moral positions that are at stake that aren't going to be sorted out simply through an appealed process. That's my hunch. And I just noticed the kind of puzzling phenomenon of putting yesterday afternoon and this morning back-to-back.

Then the other thing that puzzles me is that when advance directives first came on the scene after perhaps an initial period in which physicians weren't too positive toward them, they gradually became much more positive, I think, and the working assumption was that patients would use them to refuse treatments. Now all of a sudden, when we have by your data an increasing number of patients or surrogates using them to ask for continued treatment, they're not so good anymore. But a process solution — the advance directive was a process solution from the perspective of the patient, and I don't think it's worked that well. Why should we assume that a process solution that kind of immunizes the physicians is going to work well?

Years ago in the early years of thinking about advance directives, Robert Burt wrote a book called *Taking Care of Strangers*, and the title had a double entendre in it. It was about patients whose condition makes us uneasy, and you say, “I'll take care of them.” And that can mean several different things. And one thing it can mean is “I'll see to it that they go away.”

Burt 's claim was that what one needed was to force conversation. And I realize that it can go on a long time; it can seem impossible. But these are all attempts, whether from the standpoint of the patient or now from the standpoint of physicians, all attempts to end conversation. And I don't know whether that's the best way to deal with these problems. Neither of those comment exactly, but they're just matters that seem puzzling to me, and I'd welcome anything you want to say about it.

DR. POPE: I think there' s a big difference between advance directives and calling that a process-based approach and calling this a process-based approach, because this is a process-based approach to conflict resolution. Advance directives may be a process-based approach, but it had nothing to do with conflict resolution. I mean, we always agreed on the goal, which is we want to do — or we will do (is it a matter of public policy?) — what the patient wants. And so advance directives were just a vehicle for us to understand what it is the patient would have wanted had she not lost capacity.

DR. MEILAENDER: I don't think so. It was a way of getting an over-bearing medical

profession off of patients' backs. I mean, that's conflict.

DR. POPE: I guess my view of advance directives was that they came after the concept of informed consent. So we already have the principles. Advance directives were merely a vehicle for getting at it. It's an evidentiary vehicle but not really changing the principles. But one thing to note is, even in Texas the main defenders are very — it's not built into the statute, and it should be. But the main defenders ascribe to the AMA process, because that's where they got the statute from, and the statute in turn came from Texas . So it's a big loop. But they follow the first five steps of the AMA process, so it's not that we're jumping straight to the ethics committee invoking this formal dispute resolution.

There's a great deal, sometimes weeks or months of patient conferences, lots of communication, lots of mediation before the formal process even begins. So we're not preempting communication.

CHAIRMAN PELLEGRINO: Thank you. I am going to take the same approach I took with the last speaker since we have a time bind. We have three council members — Prof. Dresser , Eberstadt, and Gómez-Lobo — so, Dr. Pope , would you mind if we have them make their comment and you respond? First we'll ask Dr. Dresser .

PROF. DRESSER: Thank you. You have a great overview and really, I think, educated us on this. A couple of points. One is this Texas bill. It's interesting, to amend the statute. It's sort of — the idea of a process-based approach in the hospital is to avoid going to court, but in order to be acceptable as a process-based solution it has to get more like a court in that notice and five or more helpers. Is that really in the statute, five or more helpers — or the bill?

DR. POPE: The word may not have been “helper,” but it is sort of like the advocate. In other words, it doesn't need to be counsel. It could be a rabbi or anybody.

PROF. DRESSER: I see. I just wondered if you have any thoughts about what procedural protections are needed. If you were writing the bill, what would you put in there? And then secondly, just to observe that there is this overlap between conscientious objection and futility where the issue is whose view should prevail, the physician's or the patient or the patient's surrogate?

So yesterday we were talking about — some people were saying, well, the doctor's view should prevail, especially in reproductive decisions. And I think that view is influenced by a substantive view that — you know, a pro-life approach. And then today with futility we have a struggle, and the pro-life approach is against letting the doctor decide; it's going with the patient.

And so I just want to mark that. I'm not sure where to go with that, but I think certainly if we do a report on both of these issues we ought to point to the commonality and the differences and whether our views on who gets to decide are influenced by our substantive views on the particular issue they're arguing about.

CHAIRMAN PELLEGRINO: Thank you, Dr. Dresser . Dr. Eberstadt ?

DR. EBERSTADT: First I want to commend you for that very informative and comprehensive presentation. I thought that was very useful. I wanted to make an observation to which you may or may not choose to respond. It's an observation about medical contraindication of food and water, which takes a theme from the previous section and which also comes up in your presentation.

In one of the slides you presented at the slide that says “Step 3: Hospital Ethics Committee Decision,” the recommendation is outlined here: “Treatment plan for the patient be modified to allow only comfort measures such as hydration, pain control, and other interventions designed to decrease the patient's suffering.” It looks to me like a striking oversight that food isn't mentioned in there, that hydration is mentioned but not food. If it is not an oversight, it seems to me to be even more troubling.

I am not a medical professional. I am a consumer of medical services, but I don't regard food and water as medical services. There are an enormous number of life-extending measures that have been developed by humanity's ingenuity over the past generations — antibiotics, dialysis, heart and lung machines, other sorts of life-support systems — but food and water existed before human ingenuity in medicine came in to open these sorts of options for the prolongation of life.

It looks to me as if we have a paradox confronting us today with this consideration of medical contraindication of food and water, and the paradox seems to me to be this: for convicted criminals in our penal system in the United States, the idea of sentencing someone to death by starvation or by dehydration would be absolutely inconceivable, yet that possibility is not entirely remote for people in certain sorts of medical extremes. I suggest that there ought to be a sort of an ethical line in the sand regarding food and water for patients in distress.

Thank you.

CHAIRMAN PELLEGRINO: Thank you. Prof. Gómez-Lobo ?

PROF. GÓMEZ-LOBO: I'm looking at your article in the Tennessee Law Review. It's really very clear. You gave a very clear presentation of these mirror-image situations where the patients or the proxies of the patient want to continue treatment; the physicians think it's futile. On the other hand, we have the physicians wanting to carry on and maybe the patients wanting to let the person die. Now, both situations for me are very troublesome, of course, and they lead me to try to understand the force of technology and of medical technology, above all, sort of driving our culture at this very moment.

The question is a very simple one. Of those two situations, which is the most common one? The reason why I ask is because I think the popular perception is that there is more of the situation in which the technologist insists on using the technology, and it's the lay persons who want to resist that. I've been relatively close to two cases like that. So just an approximate sense that you might have of what's the more frequent situation.

CHAIRMAN PELLEGRINO: Dr. Pope ?

DR. POPE: With respect to Prof. Dresser 's comment about how to fix the ethics committee without basically converting it into a court, first I think that completely apart from the futility dispute, they need to be significantly strengthened, as do IRBs in terms of their training and their competence, their composition, and their methods. But we have models. We certainly have models to make them more fair without making them into courts. Right? We have peer review in hospitals, which works perfectly fine. We allow judicial review but we only allow the courts to peek in. So we can sort of have our cake and eat it too, which is we can say to the critical care intensivists, who are typically the ones who bring these cases to the ethics committee — the ethics committee is basically the last word. We will allow some judicial review, but that need not chill you because they are only going to check a tiny bit to make sure the proper procedures were followed.

Same thing in the business context, right? We have the business judgment rule. If you are suing the directors of your corporation because you — for example, Disney because you think they shouldn't have paid Michael Ovitz this incredibly large golden parachute — “That should have been my dividend, not his paycheck.” — again we defer. The courts won't take that because they will say that was a business decision; that was for the board of Disney to decide, not for me to judge. They will peek into the decision but only to make sure: “Did you bring in the investment advisors? Did you bring in the economists? Did you have a basis? Did you deliberate and have some information to make the decisions?” I think there are models to look to to strengthen the ethics committee without basically converting it into a court.

For Prof. Eberstadt , I don't understand sufficiently the medicine to understand when artificial hydration is medically contraindicated. But your analogy with the convicted prisoners, I don't think that that's terribly informative because the difference, of course, here

is that with the advance directives these are people who wanted this. They consented to being dehydrated. And so I don't think that there's a big difference when you consent to it and when you don't consent to it. I guess what you're now judging is the prisoner and the person you subject to this Texas mechanism so that they are both involuntarily being deprived, except again the difference is that there has been a great deal of multi — assuming a good ethics committee, lots of medical expertise and lots of multidisciplinary input that this is in their best interests, while if we did do that it would violate the Eighth Amendment if we did it in a prison context. But if we did do that for prisoners, that determination would never have been made. That wouldn't have been part of the conviction process.

I think the difficulty in answering Prof. Gómez-Lobo 's question is that you may be right that there may be — the bigger problem out there may be the aggressive doctor, not the aggressive surrogate. The problem is, to get data on that is very difficult because the aggressive doctor is going to get consent. So you don't have conflicts that are crystallized so that you can identify them. So if your oncologist says, “Look, we've had three rounds to achieve remission. Let's try a fourth round.” I mean, hardly any oncologist would probably do that, but then the patient says okay. So if you convince using — you pitch that to the patient, framing it in a way that's going to solicit an affirmative answer, you have a consensual situation, so you don't have any conflict.

So the problem is, I think there probably may be more futility conflicts than the classic right-to-die conflicts in today's world because we have such a good structure with our health clinician's laws, POLST, MOLST, and so forth that we understand that if the patient wants to stop they get a right to stop. And so when the physician is pushing, they get consent. So you don't actually have a conflict. We don't have numbers to compare there.

CHAIRMAN PELLEGRINO: Thank you very much, Dr. Pope . Are there any more comments? We have just a few moments left. If not, we'll move directly to the public testimony session.