

Health Law Journal



A publication of the Health Law Section
of the New York State Bar Association

CONVERSATIONS ABOUT

- Hospital Combinations
- Medical Malpractice
- Fraud and Abuse
- Health Care Reform
- End-of-Life Decisionmaking
- Difficult Inpatient Discharge Decisions



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Cover artwork:

Billing, Frederick William (1834-1914). *Discussion at the Continental Arms, 1861*

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A Conversation About End-of-Life Decisionmaking

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July 10, 2009

OUELLETTE: Welcome, I'm happy to see everyone here. Thank you all for joining us. I'm looking forward to talking with you over the next hour-and-a-half or so about end-of-life issues in New York. Before we begin I'd like to just do some quick introductions. If we can each give a little bit of background about ourselves, that would be great. I'll start with myself, I'm Alicia Ouellette. I'm on the faculty at Albany Law School and in the Union Graduate College/Mount Sinai School of Medicine Program in Bioethics. At the law school I teach New York Practice and Bioethics. I spend most of my research time thinking about end-of-life issues, reproductive ethics, and disability rights. Robert?

SWIDLER: I'm Robert Swidler. I'm General Counsel to Northeast Health. We operate hospitals, nursing homes, home care agencies and other providers in the Capital District. In the past I was Counsel to the New York State

Task Force on Life and the Law, an Assistant Counsel to Governor Cuomo for healthcare issues, and Counsel to the NYS Office of Mental Health. I'm Editor of the *NYS Health Law Journal*, and I'm also on the faculty of the Alden March Bioethics Center at Albany Med and the Union/Mount Sinai Bioethics Center at Union College.

OUELLETTE: Nancy?

DUBLER: I'm Nancy Neveloff Dubler. I am an attorney, presently Senior Associate at the Montefiore-Einstein Center for Bioethics, Ethics Consultant to the New York City Health and Hospitals Corporation and Professor Emerita at the Albert Einstein College of Medicine. I've written about end-of-life care, research ethics, bioethics consultation, and—especially—in the area of mediation in bioethics. I see many bioethical dilemmas as conflicts that need to be managed or resolved. I am a member of the New York State Task Force on Life and the Law and the New York State Stem Cell Ethics Research Board.

OUELLETTE: Thad?

POPE: I'm Thaddeus Pope. I'm a law professor at Widener University in Wilmington, Delaware, which is not in New York State. I teach Bioethics, Health Law: Quality & Liability, and Health Law: Finance & Regulation. I serve on a large hospital ethics committee in Delaware and on a regional long-term care facility committee in New Jersey. I've written quite a bit, recently, about medical futility disputes, about the health care ethics committee as a dispute resolution mechanism, and about advance directives. I am now on a task force to introduce MOLST (Medical Orders for Life-Sustaining Treatment) in the state of Delaware.

OUELLETTE: Great. And Dr. Quill?

DR. QUILL: Tim Quill. I'm a professor of medicine, psychiatry and medical humanities at the University of Rochester Medical Center and I direct its Center for Ethics, Humanities and Palliative Care. I'm a general internist with a long-standing interest in hospice and palliative medicine, and I now run a pretty large and growing palliative care program at the University of Rochester. I'm on the board of the American Academy of Hospice and Palliative Medicine. I've been the chairperson of their ethics committee for a year-and-a-half, and been involved in researching areas of doctor patient communication, doctor patient relationship, patient empowerment and thinking about areas of choice for patients who are struggling at the end of life.

OUELLETTE: All right. Thank you. We are going to talk about end-of-life decisionmaking. I do want to get to the

Family Health Care Decisions Act, which is, of course, a hot topic in New York law, but I wanted to start with a general question to put the discussion about end-of-life decisionmaking in context. My question is this: one of the things that I hear at academic conferences quite often is that it's harder to die in New York State than it is anywhere else in the United States. Why do you think people say that? Do you think that it's a fair statement?

DUBLER: They say it because it's true.

OUELLETTE: How so?

DUBLER: Because medicine in New York has been constrained by and deformed by the law of the state. Case law, dating from the 1980s, which has never been overruled by the legislature, which places the burden on the patient to create the terms and conditions for death rather than permitting the patient's family and physician to respond to the situation of, and the needs of the patient, as the patient nears death.

QUILL: As a clinician, I will say a positive with regard to end-of-life care in New York is a very strong penetration of palliative care in academic medical centers. There are many well-trained clinicians available to care for patients at the end of life. Probably more so than any other state in the country. On the other hand, if you have an ethically complex end-of-life decision in New York (or probably elsewhere), one of the operating principles is you almost never formally ask for a legal opinion or go to court. Because, in New York, you're going to get answers that you don't want to hear. In fact, the advice that I've been given is the courts don't want us there. But if you get into court or ask a lawyer, you're going to get information from case law and other sources that may not be helpful to you. This creates a very restrictive environment because there is a lot of fear of the law in New York State which means that end-of-life care is extremely uneven. If you are lucky enough to be taken care of by someone with sophistication and experience, you're probably going to be fine. And if you have somebody who's fearful of the law, who goes to the law first, you could be in real trouble.

SWIDLER: I agree with the statements by both Nancy Dubler and Dr. Quill. I think one of the reasons that I've been a longtime supporter of the Family Health Care Decisions Act¹ is that under the current state of the law providers have to choose between providing care that is medically and ethically appropriate on one hand, and care that is legally safe on the other hand, and they're not the same thing. So we should be changing our legal requirements, not our ethical and medical standards. So, I agree with that.

But returning to the original question, "Is it harder to die in New York than anywhere else?" I would start by noting, without trying to be flippant, that I'm sure it's hard to die anywhere. Even in Washington or Oregon, states which allow physician-assisted suicide, I'm sure patients often go through enormous pain and suffering before they get to that point where they get palliative care, withdrawal of life-sustaining treatment, or assistance in dying.

But on the issue of respecting decisions towards the end of life and fulfilling the kind of end-of-life course that a patient would want, I think New York is very strong on respecting the wishes of patients who either make their wishes known or appoint a health care agent or plan in advance. I know there are problems everywhere with overly aggressive treatments that are provided in defiance of patient wishes. I don't think that's different in New York than elsewhere. But I think that in New York providers are very respectful, and the law is very respectful, of patients who plan in advance or make their wishes known.

But the place where our law is really deficient and exceptionally harsh is in the rules governing patients who didn't make their wishes known and didn't plan in advance. That's where I think we're more harsh in end-of-life care than other states. So that's what we need to correct.

DUBLER: The problems with that analysis, Robert, seems to me to be as follows: One, we know that most people don't think in advance about what they want. Two, advance directives are very unevenly executed by patients. Three, there seems to be a correlation between socioeconomic status and executed advance directives. If you have a lawyer who does your will and arranges your estate, that lawyer will also suggest an advance directive. So that people who have property often have advance directives. I worked for 36 years in the Bronx. Most patients in the Bronx don't have advance directives. Many have been without medical care in their lives; they don't want to limit care at the end of life, which is usually the goal of an advance directive even if the concept is value-neutral; they want access to care. I always like to comment when talking about ethical issues, that access to care, fairness in health care and universal coverage by medicine complicate every problem including end-of-life care.

POPE: I was just going to say the problem results from a combination of not just the absence of the Health Care Decisions Act but also from the presumption in favor of treating. It's the combination of the two that means, unless you have an advance directive, which 80% of the people don't, or unless you have clear,

convincing evidence of what the patient wanted, then the presumption is to continue treating. Now, I think Dr. Quill implied, or suggested, that some people are less risk-averse and are willing to “polish” the family’s recollections of the patient’s preferences, so the current standard can be satisfied. Even today, where there is consensus and agreement, things work at some manageable level. So, I guess what I’m trying to do is “target down” exactly why it is so hard to have a “good death” in New York. In short, there is giant gap, a chasm between the law and what people think proper medical practice is. I am not suggesting this as a realistic option. But I do want to note that the gap might be narrowed or closed without legislative action, if providers were less risk-averse and more willing to fudge or polish evidence of patient preferences.

OUELLETTE: What do you mean by fudge and polish?

SWIDLER: I do a lot of fudging and polishing so I can answer that. It describes when hospitals, and hospital counsel like me, struggle to find a way to square the circle, to reconcile compassionate care with the unrealistically high clear and convincing evidence standard that the law demands for limiting life-sustaining treatment.² So what we do, frankly, is find clear and convincing evidence in the strings and bits and pieces related to us by family members.

DUBLER: But, Robert, what you’ve just described is a dysfunctional system. It demonstrates precisely where the goals of medicine are deformed by the demands of the law. So everyone fudges and polishes and encourages family members to provide information that will permit compassionate and appropriate end-of-life care. Consider the case of a Yugoslavian immigrant family. A beloved 98-year-old matriarch of the family had experienced an overwhelming stroke. She had no possibility of recovery to a state where she could ever recognize or respond to loved ones. She was intubated, stitched together with wires and tubes. She had led a good life and was at the end of that life. The family was desperate to let her die. They stated, “How could she have told us that she didn’t want a ventilator? She never knew a machine like this existed.” What a terrible thing to do to families at the end of life. We basically encourage them to create a fiction to fall within the law. And what a terrible thing to do to physicians; we force them to think about these inappropriate legal stipulations when their goal should be compassion and care.

DR. QUILL: There’s no question that there is a large gap between what clinicians, patients and families are facing and what the law says to do in New York, making the system at times very dysfunctional. Some of the end-of-life legal standards in New York are completely

unreachable clinically. For example, the “clear and convincing standard” for allowing for someone without capacity to forgo a ventilator or a feeding tube is in most cases impossible to attain. You will find huge variation in how much leeway families are given to refuse such treatments for their loved ones who may never have considered these options in the past. So, in that sense, the current system is completely dysfunctional and arbitrary in terms of how much discretion families are given to make these important decisions. The Family Health Care Decisions Act, if passed, will empower caring families and clinicians to make the best decisions they can under all that clinical uncertainty. In that sense, it is hugely important. In fact, it’s more important than advance directives because the data say that the way we imagine our future as healthy people is not necessarily the way we are going to want medical decisions to be made when we’re sick. So advance directives, even if completed, don’t rigidly solve these issues either. It’s still going to be this complex group of people sitting down and doing the best they can. And the Family Health Care Decisions Act, as I understand it, really is going to allow that to happen. So it’s going to close a lot of gaps where we are currently pretending to have more clear information than we really have. The application of standards of evidence is very arbitrary and inconsistent. Depending on the clinician’s personal values and fear about the law, you are going to see tremendous variation in how the “clear and convincing” standard is applied. And nobody wants us to get into court on these cases, as being a test case is potentially frightening to all involved.

OUELLETTE: Speaking of dysfunction, let’s turn to the New York Legislature. When we first planned the panel, Robert had assured me that this was the year that the Family Health Care Decisions Act would pass through the Senate. Our thought was that the panel would educate the Bar about the new law, but two days before we thought there would be a vote to pass the bill, there was instead a legislative coup. Things fell apart and business stopped, or had stopped until sometime around 10 o’clock or 11 o’clock last night, when business in the Legislature picked up again. So I’m going to ask Robert to fill us in about where we are with Family Health Care Decisions Act.

SWIDLER: Sure. The Family Health Care Decisions Act (FHCDA) is based on a proposal by the New York State Task Force on Life and the Law, and was set forth in a booklet in 1992, 17 years ago, called *When Others Must Choose*.³ The Task Force noted the same problem then that we’re noting now: that it’s unrealistic to expect clear and convincing evidence that a patient would want to forgo a particular treatment under a particular circumstance. And that as a result we’re putting physicians and families in an intolerable situation where they either have to get treatment that is unduly burdensome toward the end of

life, or they have to go outside the scope of what the law permits to allow compassionate care.

The Task Force also recognized that that the problem of surrogate decisionmaking is the bigger part of the problem that will not be solved by advance directives, just as both Nancy and Dr. Quill recognize that this is bigger part of the problem. So they proposed a surrogate decisionmaking law that says, “In the event that patient loses capacity and the patient didn’t appoint a health care agent and didn’t leave clear and convincing evidencing or make the decision themselves, then you go to specified family members for the decision, or if there’s no family member, then to a close friend, and the family member can make health care decisions for the patient based on the patient’s wishes if reasonably known, or else the patient’s best interests, and if it’s an end-of-life decision and the patient meets certain strict clinical criteria, then the family member can make the decision to withdraw or withholding of life-sustaining treatment, without clear and convincing evidence, but based on the patient’s wishes, if reasonably known, or if they’re not reasonably known, based on the surrogate’s assessment of the patient’s best interest.”

What’s interesting is that bill has been around now 16 or 17 years and I think for the past six, seven maybe even longer years, there has been broad consensus on the need for the bill and the basic principles of the bill. But it was hung up on two ridiculous side issues, in fact on two ridiculous *words*. One was the word “fetus.” For years, the Senate wouldn’t consider the bill unless there was some recognition in it that if an incapable patient is pregnant, the surrogate should consider the impact of the decision on the fetus. The Assembly would not agree to that. The other word was “domestic partner.” Okay, that’s a phrase, not a word. Anyway the Assembly said when choosing the surrogate, a top category should be the “spouse or domestic partner.” The Senate wouldn’t address the bill with that phrase in there.

Well, the State Senate became Democratic in 2009, and the new Health Committee Chair, Tom Duane, went over and took the Assembly position on both those issues and put in a “same-as” bill identical to the 2008 Assembly bill. That resolved those two longstanding issues and really created the ground to get the bill passed this year.

As a result of that, there was a lot of activity in the Spring 2009 with people now taking the FHCDA very seriously, and working on some of the technical questions with the expectation that it might really finally become the law

So recently there have been new issues that have become the focus of discussion. But these are more the type of issues that arise when policymakers agree on the key substantive matters but are trying to anticipate

and address the implications of a complex bill. One of the issues is how should the bill apply to persons with mental retardation or persons in mental health facilities because both of those populations already have surrogate decisionmaking laws,⁴ and those laws differ a little bit from the terms of the Family Health Care Decisions Act. And the resolution ultimately, and it may just be an interim resolution, was that the FHCDA should provide that , if you’re mentally retarded and a decision can be made for you under what’s called the Health Care Decisions Act for Mentally Retarded Persons,⁵ then that law applies, not the FHCDA.

And if you are mentally ill and you are hospitalized and OMH regs provided for surrogate decisionmaking for you, then those regs apply, not the FHCDA. But that approach was regarded simply as a placeholder until there is further study about bringing those populations within the scope of the FHCDA.

The only other issue that was the subject of a lot of discussion was the question of where this law should apply. Prior drafts had not been very clear about all the different settings in which the FHCDA would apply. It clearly applied in hospitals and nursing homes, and the bill designed many safeguards with those settings in mind, like the expectation that hospitals and nursing homes would convene ethics committees and have the ability to secure concurring opinions of incapacity from professionals with specific qualifications.

But it became much more complicated to think how would this apply to a surrogate decision for an incapable patient in a doctor’s office, or in home care, or in an ambulatory surgery center, or a physical therapist’s office. So the bill was amended in 2009 to specify that at least initially it applies only in hospitals and nursing homes. Then there was a lot of discussion about the extending the bill to at least cover hospice patients in whatever setting they are in. But for the moment it just applies to patients in hospitals and nursing homes.

So in May and June, I was invited to some of the legislative meetings on the bill as a technical resource. And on June 6, I was packing my briefcase to go to a meeting of Senate, Assembly, and Governor’s Office staff to walk through the bill one last time, to make sure that there were no final technical issues, and to reflect some of the comments that had come in the previous week. I was already thinking about the post-enactment party that we would have to celebrate it being passed. That was the day that there was a coup in the Senate, and then the Legislature became deadlocked and nonfunctional for a very long period. A situation that was just remarkable and unprecedented. Those of us who have been in Albany for a long time have never seen anything as chaotic as

this. And it just brought a halt to all legislation, including the FHCDA. This event was just about the only scenario that could derail the FHCDA at that point, and indeed, it derailed it.

But there are still hopeful signs. In particular, the Senate recently updated its bill to reflect the Assembly's 2009 bill, and is advancing it in the Senate. So I am still hopeful something will happen this session.⁶ Over the past three months what I've seen with this bill is, "It's dead! No it's alive! No wait, it's dead! No it's alive," and this is another reiteration of that. It's exciting, and I think the prospects have been resurrected for the moment and I'm hopeful that it will pass. And if it does pass, it will significantly alleviate the problem that we have, where good care is not lawful care. That's simply not tolerable.

OUELLETTE: Okay, so how important is it that FHCDA pass?

DR. QUILL: The only thing I would say is that this would reconcile New York State and the vast majority of other states, and put common sense back into the process. It would allow us to do what families want us to do, which is if a person is incapacitated, sit down with the family and try to achieve a consensus about how to make the best possible decisions we can under these very hard clinical circumstances that is respectful of the patient's values and clinical situation. It is going to be a huge step forward in reconciling what we actually should do with good care and what the law said we should do. So there will still be a significant number of challenging cases where the law and good clinical care will still be somewhat at odds. People who never had capacity will still be a challenge legally and clinically, for example, but those numbers are very small and maybe those should be resolved in a more complex way. But I think that passage of the Family Health Care Decisions Act would be a huge step forward if it can finally be passed.

SWIDLER: Dr. Quill, can I ask you a question about this? One thing I often hear, particularly from doctors, "Well, it ain't broke, so don't fix it. I'm finding ways even within the constraints of the law to provide good care, I just don't pay that much attention to the limits you're talking about and I don't want things to get more bureaucratic with some law that tells me I need to determine incapacity this way, then I need document that certain clinical criteria have been met, and so on." I know there's going to be grousing and resistance about that. Is it worth it?

DR. QUILL: From my point of view, it is well worth it. When clinicians are not following standards—when we say we are going to ignore the standards and do the best we can on a case-by-case basis we know that the way decisions are made tends to be pretty uneven and unpredictable. And there are some agreed-upon,

practical ethical standards to guide these decisions, so if you have good policy and good law, we ought to be able to document and carry out good clinical care. Under the Family Health Care Decisions Act, if you document good clinical care, you will meet the legal criteria, and I think reinforcing that is a good thing. There may well be some grousing about new bureaucratic requirements, but having your fear of the law guiding what you're going to do clinically is just not tolerable.

DUBLER: I would add, I agree entirely. And I would add a number of other points to what Dr. Quill has said. One. Self-conscious care in making decisions at the end of life is a good thing. These are not decisions that should be made casually. The law has been most effective, when it raised consciousness regarding the gravity of the situations that are faced. Two. The burdens appear to be reasonable in this law. There are, however, always unanticipated negative consequences of any legislation. In this instance, I am concerned about home care and the hospice setting. Although I think the hospice setting is sufficiently self-conscious to not be disturbed by the law.

What this new legislation will do, hopefully, is remove the law from the clinical setting. What the present legal structure has done is make it comfortable for lawyers to say we have a role in clinical-care decisions. And what I hope this bill will do is to return these decisions to the bedside where loved ones and physicians can jointly fashion a care plan that is appropriate and kind for this patient.

DR. QUILL: The home care gap is a huge issue in the sense that at the end of life generally you want to keep people out of the acute hospital, and many people would much prefer to die at home and not in a nursing home. Whatever the standards are for the hospital and the nursing home, they should be followed in the home care setting, even if that's not what the letter of the law says. So this could be an area where there's a small gap. But I don't see having to admit somebody to the hospital to make a decision that could have been made at home. That would be ridiculous. But I do think if you had a standard in the nursing home and the hospital that people will generally follow that same standard at home, even if that's not within the letter of the law.

DUBLER: The decisionmaking that goes on in the hospital as part of the discharge planning process will need to assume the burden of this decision. It will take some creativity to make it happen, but I, like you, Dr. Quill, think that it's probably possible to set up some guidelines and standards that will extend the reach of legislative intention into the home.

SWIDLER: Nancy, I agree with you. That was the exact point, you made the same point I was going to make,

and better than I would have made it. But for your information, I had this question from the state hospice association: If, after the FHCDA is passed, the patient is in the hospital or nursing home, more likely hospital, and is discharged to home, with surrogate consent to a care plan that provides for palliative care and comfort care only, can the hospice program then honor that in the home? And I think the answer, clearly, is yes.

DUBLER: Yes.

SWIDLER: The decision was made lawfully per the FHCDA in the hospital setting by a surrogate. There's nothing in the FHCDA that tells you that same decision should be disregarded when the person has stepped outside the hospital. But what we still need to do, though, is find appropriate ways with appropriate safeguards to extend the law to decisions that are initially made in the home and in the doctor's office and in the ambulatory surgery center.

DUBLER: Yes.

SWIDLER: But I think there may be a need to think more about what those safeguards are. Because the safeguards in the hospital, for instance, the ethics committee, are not going to extrapolate well or easily to a decision made at home. So, we need to think about that.

DUBLER: I would suggest, however, that the "best is the enemy of the good." At this point, 18 years into the process, I'm willing to take the good and proceed from there.

SWIDLER: Here, here. One other point Dr. Quill made is that there are still going to be a lot of problems this doesn't solve. One of the biggest problems it won't solve, and I think this is a source of misunderstanding, is the Terri Schiavo-type problem. The family dispute. People have come to me and said, "Oh, is this law designed to solve the Terri Schiavo type problem?" And it clearly is not. What this law does is enable a decision to be made where there *isn't* a dispute, which I think is the main problem in New York. Right now we can't even make end of life decisions when everybody is in agreement on it. But when there is very sharp disagreement and somebody wants to go to court, well, yes then there's going to be a court proceeding. And the issue will be whether what reflects the patient's wishes, if known, or the patient's best interest if not known. And that could get litigated and that could get appealed and that could become politicized. So the FHCDA is not an inoculation against a Schiavo problem. It just makes good medical practice lawful.

DUBLER: Many disputes at the end-of-life can be mediated. By empowering the parties, hearing their voices, enlarging options and devoting focus and

time to the project, many disputes can be resolved. However, some disputes cannot be either managed or resolved. Disputes that are animated by hatred, mistrust, and ideological chasms must be referred to courts for resolution. That is the usual and comfortable role for judges to play.

POPE: I certainly support the Family Health Care Decisions Act, like everybody else. But in a sense it not only fails to solve *Schiavo*-type problems, it also actually seems to create such problems. By demanding advance directives and clear and convincing evidence, the current law sets an unrealistically demanding standard. Still, it is a nice ideal, because it maximizes, we think, the idea that we're best protecting the patient's authenticity and the patient's autonomy. We want—under current New York law—solid, very, very good evidence that what we're doing is what the patient would have wanted. Absent that, we're going to presume that life (in any almost any state of sentience or suffering) should be prolonged and that life-sustaining treatment should not be withheld or withdrawn. Now, under the proposed Health Care Decisions Act, merely by status, without any evidence, merely by status, the surrogate is empowered to make medical decisions on behalf of the patient. That should cause us a little pause because we know that the uniformly consistent evidence is that surrogate decisions diverge from patient instructions, preferences, and best interests. Surrogates often do not really know what the patient would have wanted. And even if they do know, they often choose treatment different than what the patient would have wanted. This is why I am suggesting the FHCDA may create more *Schiavo*-type conflicts. Under the FHCDA, you are going to have surrogates who are going to get challenged by both other family members and by providers. And even if they are not formally challenged, even if it never goes to litigation, we know, statistically, that there are going to be many surrogates, who are legally authorized decision-makers, who are probably not making the decision that the patient would have wanted. The overall good achieved by the FHCDA surely outweighs any problems that it creates. As Nancy suggested, this may be one of those things that while, not perfect, creates overall good on balance.

DUBLER: Thad, I think you've raised a number of very interesting problems. One is, the New York State case law that put us in the bind that we now find ourselves begins in 1981. In 1981 it was important to emphasize the autonomy of the patient. In the dynamic of the history of the doctor-patient relationship, it was important to say, at that time, autonomy rules. I'm one of the people who now think that autonomy as the single organizing principle of medicine has diminished power and force. Individual wishes are important. Individual rights are important. However, there are other equally valid issues in end-of-

life care. Like what the patient can foresee, what suffering the patient is undergoing, and what people of good will and skill can bring to a discussion of the patient's best interest.

The default notion that death is to be avoided at all costs is, I think, morally deficient as a way of responding to the human condition. So I am comfortable in saying ethically, that autonomy, in and of itself, is the only factor that ever matters, which is basically what New York State case law states, is rigid, overly simplistic and deficient in nuance, compassion and a broadly humanitarian view of the human condition.

From my perspective as a communitarian, from someone who thinks that the greatest ethical problem in American medicine is the lack of access to care, for those people who are uninsured, the notion that individual rights should always trump is one that I find increasingly obnoxious. As we move into discussions of extending care and health care coverage, autonomy as the single defensible principle for distributing care must be re-examined.

I realize that one should never talk about rationing. But one has to talk about the fair disbursements of the goods of medicine. So from the perspective as a citizen in this nation and from one who looks at the struggles of physicians and families at the end of life, I'm not distressed by the notion that autonomy is not the only or even the single most important issue to be grappled with.

QUILL: I agree with you in general terms. In practical terms, working with a family to try to protect and represent the patient's autonomy is still a very fundamental issue....

DUBLER: Absolutely.

QUILL: ...and as you're trying to figure out what a person would have wanted when they cannot speak for themselves, getting a family together to imagine what the patient would say under this very special and particular circumstance is the fundamental challenge. If and when the Family Health Care Decisions Act is passed, the job clinically and ethically will be reconciled with the job legally. This will be a huge step forward for the state.

DUBLER: I agree entirely. Which is why when I sit down with a family, and I always sit down, the first question I ask is, "Tell me about momma." Because the physicians are experts on medicine, but the family is the expert on momma. And they are experts not only because of what she said and made explicit in discussions, but because of who she was and what she presented to her family in the web of relationships that she established. So we agree entirely.

OUELLETTE: To follow up on this sort of scenario that we're talking about, how would the Family Health Care Decisions Act help when there is a conflict in a *Schiavo*-type scenario, between what the appointed surrogate wants and what another family member wants? What's the mechanism for challenging that decision? Does it involve ethics committees or going to court, as Nancy suggested?

POPE: Well, it could involve both. Initially, the FHCDA provides for an ethics committee to act in dispute mediation or make an effort at dispute mediation. I must also point out that nature has a way of solving an awful lot of these disputes. Many times, the patient dies during the course of the dispute, no matter what efforts are made. But under the mechanism of the Family Health Care Decisions Act, there is dispute mediation. If that doesn't resolve the issue, the surrogate's decision can be honored. But either party can go to court and try to get a different decision.

QUILL: Practically, there is a sequence that usually occurs. In these tougher cases, if you have palliative care consultation available, they get involved and try to mediate the dispute and achieve a consensus. If they can't resolve the issue, then it's the ethics committee that gets involved next. They try to reconcile the parties, and if that can't happen, then it goes to court. So there are mechanisms for dispute mediation that don't involve the courts that are actually quite sophisticated at most major medical centers. So in the cases that actually get to court, there's already really been a lot of effort to find common ground and to invent solutions.

DUBLER: I just want to drop a footnote to Dr. Quill's statement since I've written widely about bioethics mediation. I tremble, gently, to say that mediation requires skills. There is formal training in mediation and dispute resolution and a body of materials to be mastered; the reason I was drawn to mediation is because it contains a litany of skills that I can teach. And therefore I think it will be extremely important if this law passes to be certain that we really provide professionals with the skills to do the tasks that we ask them to do.

POPE: I have a comment and then a question. Mediation takes care of most end-of-life disputes—mediation in one form or another.⁷ But when these sorts of disputes do reach the courts, judges seem increasingly willing to replace errant surrogates. For example, surrogates who are asking for treatment that's contrary to the explicit instructions in the patient's advance directive are replaced with another substitute decision-maker. One example is the Dorothy Livadas case decided by a Monroe County court just last year.⁸

In Ontario, they have a whole special mechanism just to do this: the Consent and Capacity Board. If an Ontario healthcare provider thinks that what the surrogate is asking for is contrary to the patient's known preferences or (if we don't know what those are) the patient's best interests, then the provider can go to the CCB and have somebody else appointed as decision-maker for the patient.⁹

In New York, Massachusetts, and other states, this surrogate replacement is happening more and more. That case law is starting to cast a shadow on what happens in the informal, intramural resolution process.¹⁰

That is my comment; here is my question. I was wondering if and when the Family Health Care Decisions Act gets enacted, whether the sort of conferences that Nancy was talking about would change. In the FHCDA world, it seems there might be less incentive to try as hard. In today's world, you don't have anybody who's legally authorized to make the decision. So you must get everybody together and get them talking. Now, under FHCDA, if the legally authorized decision-maker is daughter number two, it seems that you do not really need to talk to all these other people. You do not need to go through such an elaborate process. I am not suggesting that Nancy would do this. But some might slack off because there would be less incentive to be thorough.

DUBLER: I don't think so, because as clinicians know, disagreements within the families are very disruptive to the process of providing care. And so it's not the letter of the law that governs, but rather it is the comfort of the clinical setting. If there is real discord among the surrogates, that must be resolved for care to go forward even if one of the family is the legally appointed decider. Some scholars have argued that surrogates decide as much on the basis of what they think their siblings and family will bear as what they think the patient wanted. That may be one of the reasons you see the data on the discrepancy in surrogate decisionmaking. Whatever the reason, discord within the family disrupts the provision of care. Therefore, you really have to intervene as aggressively as possible to try to resolve disagreements.

Even if there is a health care proxy that the patient has named, you are still, at a practical level, sitting down with that proxy and the rest of the family and imagining what the patient would want, even though the named person's opinion of what the patient wants is given more weight perhaps than the others. If there is genuine disagreement and fulminating conflict, you're then into trying to engage in dispute resolution and mediation: diffuse the anger, create a level of trust, maximize the options for agreement and construction a consensus. And

so I don't see this need changing at all with this law. I think even with a named proxy, it's a tremendous task to make an end-of-life decision and it's sufficiently weighty so that you really do need a consensus. And when there is not a consensus that characterized a difficult process, that will likely require more sophisticated second opinions and expanded ethics opinions, before making a decision. When there's really a dispute in this process, I don't see that the need for dispute resolution and mediation will diminish to any degree.

SWIDLER: I tend to agree with that. In America now, families typically are dispersed, and their level of contact with patients varies. And what I see is that there often are one or two close, involved family members, and then there are other family members who are not that close or involved. And in the absence of any clear law, when an end-of-life decision arises, providers have a self-protective inclination to go track down everybody and make sure that everybody's on board with it. But if you have a law like the FHCDA, it makes it clear that any person who is in this priority class can provide a lawful decision. So if the priority class is adult children, then the provider can rely upon a decision from the closest-involved adult child, that would be the appropriate way to do it. And then you have a lawful decision from that person. There is no requirement to track down everybody, to take a vote or anything of that nature. Where several family members are closely involved, it would be only natural for the provider to discuss the matter with them together, but that would be a practice tip, not a legal requirement. So I think what the FHCDA does, ideally, is to make lawful the good practices that are currently going on.

In fact, the proposal I sometimes hear that providers should have to notify every family member of an end-of-life decision reminds me to place on the record the standard rant I have about against the "due processization" of health care decisions. [laughter]

I often talk to lawyers that conceptualize end-of-life decisions by family members as the deprivation of a right on the part of the patient. They say, "Well the most important right that a person has is the right to live, and you're depriving them of that. So, at the very least, you should first provide procedural due process—such as, notice to a broad range of interested persons, legal representation for the incapable patient, an opportunity to be heard, an impartial decision-maker, a written decision, and an opportunity to appeal that. After all, we're talking about life and death here." And that argument, well it makes me just want to, you know, shake the person, and say, "You know, this is not a capital punishment case, this is a medical treatment decision!" No one is trying to "deprive" the patient; it's not an adversarial proceeding. Rather, health care professionals and family members

are struggling to figure out the right thing to do for the patient. Those kinds of due process procedures, in my view, will harm the patients and the system through delays, expenses and burdens, will generate disputes where they did not exist before, and will likely to lead to a worse result than a better one, from both a patient's rights and medical ethics perspective. So I think the due processization of health care is the road to damnation. Nancy, I suspect you're a kindred spirit in that rant.

DUBLER: Well, I couldn't agree more. Involving clinicians is the key to getting guidelines that work. Death is often not the enemy. We don't want to recreate old paternalistic, non-transparent structures in which "pneumonia was the old man's friend" but patients die, and in this process of dying the task of medicine is to help them remain comfortable and to help their families grieve.

SWIDLER: And yes, there will be cases where family members disagree. And if the dispute is sharp enough, and can't be resolved by mediation, well that's when more formal procedures are needed.

DUBLER: These situations will demand robust interventions in mediating disputes performed by professionals who are experienced and skillful in dispute resolution. I offer one example.

I had a very interesting consultation once during which 17 family members were gathered together in a far-too-small room. One, who was the legal health care proxy, was demanding that mamma get the most aggressive care. Mamma was moribund, obtunded, and ventilator dependent following a massive stroke related to many co-morbid conditions. The proxy did not accept that mamma was dying. Many of the others could see that this powerful woman, who had been the center of the extended family both in this country and in another, was no longer there. They grieved. The proxy railed and raged. Finally, some many hours after our discussion began, he lessened in his rage at life and death and the hospital. There had been some vitamins that mamma had always taken at home, that he wanted to bring them in for her now. So I cut a deal with the pharmacy. I said "Would you analyze these vitamins and if there's nothing wrong with them, can we give them to mamma?"

This family was in chaos. This mediation, over many sessions, with different family members over many days required someone dedicated to resolving the family dynamic of conflict. Resolving conflicts in the context of a dying patient is labor intensive. It required multiple conversations to reach agreement that mamma was dying and that her son, who was the most distressed, needed support. In the process the mediator did a lot of "stroking" [supportive admiration for their love and

concern], maximizing of options for the care of mamma, small group conversations or caucuses and much listening. Was it worth the time and effort? Well, the process itself removed much of the strain from the ICU staff, lowered the tension among staff and family and ultimately permitted a family to come together and grieve together. I would argue that it was helpful.

OUELLETTE: One of the points that you raised earlier, Nancy, was about rationing care, and you made a critique of autonomy as being the driving force that keeps us as a country from talking about rationing. One of the places that rationing comes up is when a family wants everything done even when the health care team says enough, we've done what is appropriate. As I read the Family Health Care Decisions Act, that Act really doesn't address that type of situation of demanded care or what some people talk about as the futility problem. Is that an area of concern for New York? Do we need some kind of futility law?

DUBLER: Oh no.

SWIDLER: The FHCDA says that a surrogate can't demand any care that the patient could not have demanded. So the surrogate's rights are confined by the scope of what the patient's rights would be and patients can't demand futile care. But do we need a law in New York like Texas has, a law that would define this more clearly? I'd like to hear more about the Texas law first but it is an area of a lot of tension in New York.

DUBLER: I take a particular stance on issues of futility. Most of the time the use of the term "futility" demonstrates that the conversation between the family and the physicians has broken down. Futility is the trump that's brought out to say, "We won't do this." I would argue that the "futility" issue should be solved in the way other disputes are solved—by mediating.

When families say "do everything," they often don't realize what that means. They often don't accept the fact that the patient is dying. They often haven't resolved conflicts between and among themselves. So futility is not the end of a discussion for me, it's the beginning of a discussion. And my sense of the Texas law is that it's been a dismal failure.

DR. QUILL: I actually agree with that completely. Truly futile care, care that has no value and will not work, does not need to be offered or even discussed. You don't need a law for that. Surgeons don't do surgery when the patient's going to die on the table. They say, "I can't do it because it would hurt the patient." We don't do truly futile care. What the futility controversy is about is treatments of very marginal utility. So a patient might live an extra few days or an extra week with a very expensive,

invasive treatment like being intubated and put on a ventilator. It seems like there will be a lot of suffering and expensive resource utilization with minimal gain to warrant putting the patient through such a treatment. Yet in the current medical environment, such treatments are within a patient's rights to receive if they have even a tiny amount of utility and the patient or family wants it and is willing to put up with the consequences. Now, if we want think about fairness or justice and say as a society we are not going to offer certain kinds of treatment because they're so minimally effective, they have such little utility that they make no sense from a cost effectiveness point of view, then that's a whole other discussion. I believe that as a society we should have this discussion, but so far our culture in New York and elsewhere in the United States is no where near that. So, I think it's a waste of our time to have that discussion right now with regard to individual cases since there is no consensus about setting limits on treatments of marginal utility, and there is no broader national discussion about limit setting of any kind. I doubt we will get near that discussion in the current debate about universal access because it is too easy to marginalize and polarize as we look for areas of consensus, but eventually we will need to have this discussion if health care expenses are going to be kept within any reasonable boundaries.

POPE: I want to espouse and elaborate on that last point. If you can barely pass the Family Health Care Decisions Act, then you surely are never going to have the New York Legislature enact a unilateral refusal statute. I also agree that may not be a big loss because you probably do not really need a unilateral refusal statute. The overwhelming number of futility disputes are resolved informally through better communication and mediation. On the other hand, not every facility has a Nancy Dubler to do that, so the success rate is going to vary. So let's say there is a residual number of what you might say are "intractable disputes." Here, providers, chaplains, social workers, and clinical ethicists all have conferences with the surrogate. But the surrogate remains adamant and retractable. At that point, the providers might try replacing the surrogate as they did in the *Livadas* case. Only if not even that works, would one need to resort to a unilateral refusal law. In short, there are going to be very few disputes for which a unilateral refusal law would be necessary. Bob Truog, at Boston Children's Hospital, would say that current New York law can handle most of the intractable disputes.¹¹

Today, if a surrogate is asking you to do something that you think is (i) really, really bad, (ii) really causing the patient suffering, or (iii) really not what the patient would have wanted, then you could use the laws that authorize surrogate replacement and guardian appointment. In the end, there is basically one type of

case where you really can't do that, where you have an intractable dispute and cannot even use the current available legal mechanisms: the religiously motivated case. The surrogate is saying, "The reason I want you to continue aggressively treating this patient is because this patient's religion demands it." You cannot replace that surrogate because the surrogate is acting as the patient's good and faithful agent. The surrogate is a faithful fiduciary, doing what the patient would have wanted.¹²

There are many filters along the way, and very few cases will evade all available mechanisms. You can pass a law to handle those truly intractable disputes or, as Truog suggests, just suck it up, treat that patient, and live with it.

QUILL: The legal mechanism is in place to protect patients under some of these circumstances, but it takes a huge amount of time and energy to carry it out. Let's say you have clear evidence that a patient wouldn't want certain kinds of things, and you have a surrogate who his demanding those things. Your moral and legal obligation is to carry out the patient's wishes, so if mediation fails you are going to have to try to replace that surrogate. It takes a long time and a lot of legal resources to replace such a surrogate, and significant harm can happen to the patient during that period. So that is a real problem and the amount of moral distress that occurs around those cases in hospitals is tremendous because you feel like you're doing things that are absolutely wrong, and your hands are tied not to do them until you get legal authorization to replace the surrogate.

SWIDLER: If I can get in on this one. I think the place that the rubber meets the road on the futility issue is in DNR decisions. And that's the one area where I would advocate consideration for some narrow futility exception. We have an unfortunate AG opinion in New York¹³ that says that even when the doctor concludes that resuscitation would be futile, if the surrogate does not consent to the DNR order, then the DNR order can't be written. So when there is no DNR order, if this patient's heart stops, a physician responding to the code could perhaps make an on-the-scene clinical decision that this isn't going to work, or it's not working, so I don't have to keep up the pretense. But I think it should be lawful to write a DNR order on a narrow ground of physiological futility irrespective of the patient's or surrogate's wishes, because people don't have a right to demand a treatment that is not going to work.

DUBLER: But Robert, I have two responses to that. Number one, you know best that the Bar Association, the Medical Association and the Task Force on Life in the Law, in the early '90s crafted a document which created that futility exception since the law had not. This

futility exception was the narrow physiologic definition of futility: (1) It will not work—like using an antibiotic for a virus, or (2) the patient will code repeatedly in a short period of time. That consensus stood as an informal guideline until the AG’s office decided to intervene. But please don’t solve a flawed law with another possibly flawed law. The reason we are confronted with this problem is that the law codifies thinking at a moment of time. It seemed to make sense in a moment of time to have a DNR law. I would argue to you that, in general, it’s a bad idea to have laws that address specific issues in medicine. The law should address general setting of standards. Let medicine evolve publicly through discussions in scholarly journals, through developing and analyzing empirical evidence. Don’t ossify a moment in the evolution of medicine by enshrining it in law. Let medical discussion create the climate to support emerging guidelines. Let us not throw another law at it.

DR. QUILL: Futility around DNR is a big problem. The patients and families who want “everything,” and we repeatedly (and generally futilely) try to convince them to make the patient DNR because we feel it is very unlikely to help the patient and very invasive. We’ve just written a paper on this subject basically trying to reconcile the possibility of doing a very short code under these circumstances, and if nothing reverses within one cycle you stop. So again, because the repeated discussions about DNR with patients and families who want “everything” are so counterproductive, they’re so undermining of any kind of trust, that it’s just not worth it—it’s much more painful than one cycle of CPR and much more disruptive. So anyway, that’s our recommendation around this issue. It’s a very tough issue.

DUBLER: And that makes perfect sense to me. And if it comes out in the literature, let’s hope it is widely accepted; that would be, I think, a reasonable way to go. Much more reasonable than attempting to fix a bad law by what might be another bad law.

SWIDLER: That sounds reasonable to me but it illustrates what the question is, namely: What is the province of the doctor and what is the province of the patient? You’re saying how long to do the code is the province of the doctor, not the patient. But I’m thinking, by that same rationale, why can’t a patient say, “I want to be resuscitated and don’t let me catch you doing one of those short codes on me, I want the full nine yards.”

DUBLER: But, Robert, it’s never the patient. It’s never the patient. It is almost always the family. If the patient were to say that to you, Dr. Quill, if the patient were to say, “I want a full code, no matter that I’m dying,” what would you do?

DR. QUILL: Well again, what we said in this paper, and this is actually what we would do, we would do a full code. One cycle of CPR. If after one cycle there is no response and a person who had a one-in-a-thousand chance of having any response from the beginning, and there is now one-in-a-million chance that they’re going to respond for a few hours, and that meets my criteria for absolutely futility. So again, that’s a medical decision. You stop a code when it’s not going to work any more.

DUBLER: Exactly.

DR. QUILL: So there are things you might find in a code at the beginning that might allow the patient to live longer; let’s say they have a mucous plug that you might suck out and they might live another week. And so you can’t use absolute futility to not do it in the first place. You could say, “It doesn’t make sense to me,” or that “I don’t want to do it” or it is “a bad use of resources,” but you can’t use absolute futility as a way to avoid trying CPR under these circumstances, at least according to my way of thinking about futility.

DUBLER: You might call that, I don’t know what you called it in your paper, but you might call that “demonstrated futility.”

DR. QUILL: Maybe.

OUELLETTE: The Texas futility law goes far beyond CPR, right? It applies to situations where there is ongoing treatment. There’ve been a couple of cases that have generated a great deal of public attention in which the law was invoked by hospitals to terminate ongoing treatment over the objection of the families. There seems to be consensus in the group here that it’s not a good law. Thaddeus Pope is an expert in medical futility. Could you just tell us a little about the Texas law so the people who read this transcript understand what that law does.

POPE: Sure. The Texas Advance Directives Act, of which the unilateral refusal provisions are just one small part, was originally drafted in 1997, but was vetoed by Governor Bush. Between 1997 and 1999, the law was redrafted through a true consensus process. Every single relevant stakeholder in Texas participated: the Catholic Bishops, right-to-life groups, disability groups, hospital associations, physician associations. The resulting product had unanimous support, and was thereby effectively “gift wrapped” when it was sent to the legislature. It was passed and Governor Bush signed it in 1999. So, this year marks the tenth anniversary of the Texas Advance Directives Act. Alicia is correct. TADA permits the unilateral refusal of not only CPR but also any other life-sustaining treatment. So if a surrogate—and it’s almost always a surrogate, since the patients we’re talking about don’t have capacity—is asking for treatment

that the physicians think is not medically indicated, not medically appropriate, then the physician usually will try to mediate and have consultations, though that is not required by the statute. If that doesn't work, then the provider may initiate the formal process of the statute, which is spelled out in Texas Health Safety Code 166.046. The first step requires the physician to give the family, the surrogate, at least 48-hours notice of an ethics committee meeting. Next, the ethics committee will meet and discuss the case. Almost always, the ethics committee agrees with the physician that the requested treatment is medically inappropriate. The ethics committee must memorialize its decision in writing. Unfortunately, the quality of the decision process and the written decision varies tremendously because the statute is silent on key issues such as the composition and functioning of the ethics committee. Next, after the surrogate has been served with the ethics committee's written decision, the surrogate has 10 days to transfer the patient to another facility that is willing to provide the treatment that they're asking for. Of course, the surrogate (and the provider) may have already been trying to do this. Almost always, the surrogate is unable to find a transfer because, for the same reasons that the current physicians at this institution don't want to provide the requested treatment, nobody else does either. Plus, this is a case that is now patently prone to liability, conflict, and trouble. On the 11th day, if the patient is still in the provider's facility, then the provider may stop life-sustaining medical treatment over and against the wishes of the surrogate, or the patient's advance directive. So long as this process is followed, the Texas Advance Directives Act clothes the provider with civil, criminal, and disciplinary immunity. The statutory unilateral refusal process has been utilized many times across the state.¹⁴

Often, as Dr. Quill mentioned earlier, given the timing of things, you actually don't need to override the surrogate, you don't have to withdraw over objections. The patients who we're talking about are so frail that they may not actually last the full 10 days. But sometimes if they do last, then there is unilateral withdrawal. Physicians are comfortable doing that because there's no legal risk. That's basically in a nutshell how it works. But it is hardly without controversy.

During the first eight years of the statute's operation, right-to-life and disability groups found that transfers are very hard to make. I think that they initially thought that the ten-day transfer period was going to be a much more meaningful safety valve than it actually has proved to be. So, they tried to kill the statute in 2007. That failed, and then they tried again in 2009. That too failed, just a few weeks ago. The statute has also been attacked in the courts on constitutional grounds. This is an area where

the due processization of the law might be appropriate because more than one-third of Texas hospitals are state hospitals, so we have the state withdrawing life-sustaining medical treatment. It is a deprivation of life and liberty. So, you want to have due process. Given obvious problems with notice and neutrality, among other things, section 166.046 has been repeatedly attacked as violating procedural due process. Still, no judgments have been issued because the patient invariably dies during the litigation. The family then loses interest in the case and voluntarily dismisses. Notwithstanding its due process defects, many people perceive TADA as a success because it's an effective vehicle that permits physicians both to practice what they think is good medicine and to avoid being forced to practice bad medicine by the fear of liability brought to bear by surrogates. A lot of great data has been published by Bob Fine at Baylor. Other states have explored copying Texas' unilateral refusal provisions: Wisconsin, North Carolina. The Idaho Senate passed a bill earlier this year.

OUELLETTE: So the upside of a TADA-type of law would be that it allows physicians to avoid practicing defensive medicine at the demand of surrogates. What's the downside to it? Nancy, you said it is a bad law—why would it be a bad law?

DUBLER: The major downside, in my judgment, is that physicians will have far less incentive to really talk with patients and families. And again, it will be largely families. And I think, from experience, that that incentive will increase commensurately as the socioeconomic status of the patient and family declines. I am always concerned about the fact that American medicine is largely peopled by professionals who are white, and that people who happen to be of color or of a lower socioeconomic class, who don't have the same language, the same intellectual fighting words, the same connections, or the same culture of discourse as we do, will be disregarded. I don't know what the data shows on the sorts of families who've been trumped by futility discussions, but it makes me uncomfortable that this is a trump card that will not require physicians and the institution to engage in mediation and dispute resolution. It does not require the institution to be certain that families understand. I think it interferes with the good, although labor-intensive practice, of medicine at the end of life, which Dr. Quill so eloquently exemplifies.

POPE: I think you're right. As you know, the people who are most adamant, most demanding of aggressive end-of-life care happen to be from a lower socioeconomic class, black, and Hispanic. So, those populations are most often the subjects of the implementation of the Texas Advance Directives Act. Now, there is zero evidence that the unilateral refusal provisions were used against a patient

specifically because of their wealth or race. Correlation is not causation. Still, you're absolutely right that they are overwhelmingly the population.

DUBLER: But that should give us huge pause. When the AIDS epidemic first came to the Bronx and there was a huge push in the white/gay community for advance directives, we had patients of color who weren't concerned about limiting care at the end of life, they were concerned about "access" to care. And I come back to access to care. If you have a law that's disproportionately used against people of color, that's a bad law. And therefore, the fact that it would be considered by other legislatures in other states is, as far as I'm concerned, an outrage. I apologize for the outburst but I have some passion on this subject.

DR. QUILL: You simply can't define futility in a way that makes sense clinically. You can say it did not work in the last 100 cases or the last 1,000 cases, but you can't consistently define futility in a way that is clear enough to trump a family's wishes. You do find tremendously variability about people's threshold for what is considered futile care. And again, those thresholds may vary about whether you're like me or different from me, white or black, rich or poor. So for me such definitions of futility are not helpful. Now if we're talking about lack of utility and introducing issues of societal good and justice, that's a whole other discussion, but we are not having that discussion as a culture right now in this country.

DUBLER: If we want to talk about futility in the terms that were framed by Atul Gawande, in the *New Yorker* piece of about a month ago, about the misuse of resources in Texas, or if you want to talk about David Leonhardt's piece yesterday in the *New York Times* about how to deal with prostate cancer, if we want to talk about futility in terms of national policy that will affect all people equally, then I'm with Dr. Quill. Let's have that discussion. But if you want to talk about trumping grieving families who have insufficient support at the end of life, I think that is moral outrage.

SWIDLER: I make a distinction here. I don't think there's any escaping the futility issue. Clearly if you're looking at a PVS patient, that to me is a value judgment, not a futility issue. If a family believes that that existence has quality of life or the patient would want to be maintained as long as possible, that is a judgment call that belongs to the patient. On the other hand, when you get to the issue of whether somebody ought to have a heart transplant, there's a big difference between a 60-year-old with heart trouble and a very frail end-stage Alzheimer's patient with heart trouble. And the answer to that

DUBLER: But that's not futility.

SWIDLER: Let me just finish. Of course, we wouldn't offer this to the end-stage 95-year-old because it would be futile because they're not clinically appropriate for it. All you've done is really say, "Here's an example of pure futility so nobody would do this." But there will be close cases concerning whether somebody is a candidate, where the doctors are saying they're not and the family is saying they are.

DUBLER: But that's a really good example of where the futility discussion is not relevant. There you have a clear algorithm for the allocation of scarce resources. And for this allocation of scarce resources, we have actually engaged in a national discussion which is reflected in the rules and the procedures of United Network for Organ Sharing. And therefore, futility simply doesn't enter the discussion. You have guidelines and rules for who is appropriate for a heart transplant that does not involve futility but looks at the appropriate use of a scarce resource.

SWIDLER: And if I change the example to open heart surgery, would your analysis change?

DUBLER: It depends on whether open heart surgery is a scarce resource. And whether the surgeon thinks that he or she may benefit the patient. You may have an elderly patient who is otherwise healthy, who would be an appropriate candidate for open heart surgery. Now, if ...

SWIDLER: I don't want age to be a qualifier.

DUBLER: Okay.

DR. QUILL: This is a discussion about marginal utility. It's about cost-benefit analysis. It is not about futility. I just consulted on a 95-year-old man, huge decubitus ulcers in the intensive care unit, on a ventilator from which he is not going to get off alive. Is a ventilator futile for him and should we stop? The consensus was that he would prefer to be on the ventilator and alive than off the ventilator and dead. He eventually regained capacity, and confirmed we were following his preferences. Now was it futile to put him on the ventilator? His quality of life was not something that I would found acceptable, but it was okay with him. It was probably not a good use of resources for us as a society, but for him as an individual it was clearly what he wanted under the circumstance. So we are not having any systematic societal discussion about limiting the resources being allocated to any individual patient. You can't trump his request based on futility, and it can't currently be overridden because it is not a good use of society's resources. It's a case of marginal utility. It's a cost-benefit analysis that as a society we are not yet mature enough to have.

SWIDLER: I'm not sure I see the difference. You're saying that a doctor cannot decline to provide requested care

based on futility, but can decline to provide requested care based on a cost benefit analysis. That seems to me to be the more problematic basis.

DR. QUILL: No. I'm saying you can't deprive somebody of care in this society based on a cost-benefit analysis or marginal utility. That is a subject that has to be negotiated with the patient, or usually family, in these circumstances. And using futility to unilaterally avoid that discussion (which is a hard discussion) would be very tempting because it doesn't make sense to me, and doesn't seem like a good use of resources. But we don't have a consensus as a society about these matters, and therefore I think we shouldn't be using futility to override patient and family decisions because it's going to be done very arbitrarily, and you get into everybody's biases confounding the picture.

SWIDLER: Thank you. I have to say, it's not like I have a strong view on this issue that I'm promoting. I'm struggling with the issue myself. And this is helpful. So thank you.

DUBLER: At this point I would like to contradict something that I stated earlier on. This is a circumstance in which autonomy does trump. It's very difficult to say to a patient who is capable of making health care decisions and aware of his or her surroundings, "I will not keep you on this ventilator." And I think in this instance that the patient's wishes become the absolutely dominant factor in decisionmaking. But I want to emphasize what Dr. Quill said, which is, these legislative approaches to futility provide a club that permits physicians to beat back uncomfortable wishes of patients and families without engaging in the very difficult and time-consuming discussions that are required.

Furthermore, even this small vignette might change in the event of a swine flu epidemic. In the event of an epidemic it might be necessary to allocate ventilators and to remove some patients from ventilators even if the family objects. It will be even more difficult if the objecting agent is the alert and aware patient herself.

POPE: I would like to play the other side a little bit more. Your point assumes that surrogates don't already have a club. I actually am very critical of the Texas mechanism as currently implemented, not in concept. But a strong argument in defense of a Texas-type mechanism flashed into my mind when Dr. Quill mentioned the code, although he may have been talking about something different than this. I remember the Queens Hospital grand jury indictment back in the early 80s. They were doing the purple dots and things like that; they were making unilateral futility judgments. "CPR is not appropriate for these patients." They never got consent; never discussed it with the family. And I think that

the current evidence suggests that, nationwide, there is significant "underground" unilateral refusal of life sustaining medical treatment. Providers often are not open about it. If you don't think you're going to get consent, or if you've already tried to get consent and failed, then you have to be secretive about it because it's not really allowed. And so the argument in defense of a Texas-type mechanism is similar to one employed in defense of physician-assisted suicide. It is already being done, but covertly where it is far more subject to abuse. So, why not create a mechanism, so at least it can be done transparently, openly, and regulated by a fair process?

DUBLER: I think the reason for not so doing is that the creation of legislation reflects the values of stakeholders that may not necessarily reflect the values of medicine. We are now engaged in a much more transparent practice of medicine than we had in the 1980s. When I began working in a hospital we had boards with little dots on them indicating resuscitation status, and shift wars where a patient would be DNR from 8:00 in the morning to 4:00. It was ridiculous. But I think there is a generally accepted openness about ethically fraught issues in medicine today. Scholarship regarding the ethical guidelines for patient/family/physician decisionmaking is published in major medical journals. Discussions are held in public, in the media, in the press about these decisions. The danger of legislation is that you codify thinking at a moment in time which may not reflect later thinking.

DR. QUILL: There are some real challenges and subtext issues here because you want doctors to exercise clinical judgment, and there are things that don't get offered because they are truly futile or because they don't make sense. But when there are treatments of substance that are not going to be offered or that you are recommending against, you really do want that to be the subject of a discussion. CPR is a paradigmatic case. It is both a real issue and it's a metaphor for talking about how sick and near death a patient may be. The patient is dying, but that does not give a clinician the right to unilaterally withhold potentially effective treatments even if effectiveness is marginal. If you're not going to use antibiotics to treat pneumonia because the patient is dying and you don't think it makes sense, that's going to have to be discussed. If you're going to stop checking bloodwork four times a day and instead you are going to do it once a day because it makes more sense in that circumstance, that seems to me a clinical judgment because otherwise you're just burdening people with every conceivable possibility in making them make a decision. On the other hand, if you were to stop checking any bloodwork at all, that would be a substantial change that would need to be cleared with the patient or surrogate.

DUBLER: And also, it is mean. It's mean to treat the family at the end of life as if they were some sort of junior consultant. They are not. They are grieving family. The skill and real honor of medicine is in the ability to make difficult decisions. What burden do I as a physician bear and where do I need to involve the family? And intruding into this delicate emotional and professional fabric with legislation does not generally help matters.

POPE: I think it's worth mentioning that while we can use Texas as a convenient target, Texas merely codified the AMA policy on this. And the AMA is hardly the only national professional medical association to endorse a process where the last step in the process entails unilateral refusal.

DUBLER: I think they were wrong.

POPE: Okay. Right. I just wanted to flag that this isn't just about Texas. There's a much broader support for the concept of having a mechanism like Texas than it might appear, since only one state has a law like this.

OUELLETTE: And there are at least some cases that have come out of Texas that have wound up in the courts where there's been young children or babies and the doctors really felt that the children were being harmed by the care that the mother was seeking. For example, there was the Baby Sun Hudson case,¹⁵ and the Emilio Gonzales case.¹⁶ I don't think that the physicians in those cases were trying to do harm in the family in any way; they were trying to do what they thought was right for the patients. So it may be that legislation isn't the right tool to address the problem, but there may be cases where providing the care that is requested that would prolong a life that is painful to someone who can't speak for him or herself. That is really not something that should happen. So that there's a huge difference, I think, between the case that Dr. Quill described where someone could speak for himself and say this is what I want and a case where there may be a child or someone who is being actually harmed by being kept alive.

SWIDLER: Well, Alicia reminds me that in New York we have had a couple of cases of babies or small children who had been declared brain dead where the hospital wanted to discontinue ventilation from the brain dead patient, but the parents objected to it.¹⁷ And in at least one of those cases the hospital was authorized to discontinue.¹⁸ It's analogous to the futility case, but it is placing the hospital against the patient or against the family in that the hospital's advocating the discontinuance of treatment.

DR. QUILL: In that circumstance, you have a societal consensus that if you can be declared brain dead, you are dead. There is a legal, ethical and medical

consensus on that point. In other cases, whether it's with children or with the elderly, clinicians are going to have to partner with families in deciding which treatments can be stopped. Physicians are not going to be able to unilaterally stop treatments that have an even minor utility, even if suffering is high and it seems harsh to continue with treatment, without an in-depth conversation with families. But if there is a family consensus that treatment is not serving the patient's interests and therefore "futile" using a common sense definition and the doctor's agrees, then you can stop. So I think there is some ability to stop treatment in New York, but you have a consensus-based definition that it's futile or it doesn't make sense because suffering is too high and the prognosis is too poor.

DUBLER: There is an ethical formula often used in cases with children that does not require legislation; if physicians determine that what the families are demanding would cause harm, pain and suffering to the child without compensating benefit then it is appropriate to say to parents, after a deep and engaging discussion, "We will not perform that intervention. You are welcome to take the child to another institution." If parents refuse care that is clearly in the best interest of the child, is uncontroversial, and would relieve suffering, then it is appropriate to inform parents that the intervention will proceed. And, in the great, gray middle where uncertainty looms large, the parents must choose. However, implementation of this, and other such ethical/medical algorithms, does not require new legislation. These discussions evolve as our database increases and sophistication about decisionmaking is honed more finely. I would argue to you, Dr. Quill, that if the family for the 102-year-old patient wanted an intervention that you thought would cause great pain and suffering to the patient without compensating benefit, my guess is you would say no. But very few interventions fall in that narrow bright and brittle category.

DR. QUILL: And there are processes for working on those issues. I would say "no" and if the family really disagreed, then we would probably sit down together and see if we could find a common ground. If we could not achieve agreement about what we will do and what we won't, and the differences were substantive, then we go to ethics consultation. Only if that failed, and we were really at an impasse again, would we go to the courts. *Livadas* would be a good example of that. In this case, there were clear clinical criteria for stopping treatment, and family would not consent to stopping. We went through this sequence. Now this process for *Livadas* took six months before we actually stopped treatment based on brain death criteria. So it took this long even in a clear-cut case. Now one could argue that the patient probably was not harmed because she was so brain injured in the

first place that she was not aware enough to experience suffering, but I don't find much solace in that argument, and she clearly was harmed in significant ways. It's a very long process to go through all these steps, and there is significant suffering all around in this process. And the staff providing care that was extremely invasive, seemed to be inducing suffering and didn't make any sense to them for six months. They felt like we were working against this patient's expressed wishes, and she was suffering significantly in a way that could only end in her death. So again, there are many layers of harm that can happen in these cases.

POPE: I think this is actually right in the Family Health Care Decisions Act, the bill. Say that you are a physician and the authorized decisionmaker asks you to do something that you think is medically inappropriate. You cannot convince them otherwise. In that case, transfer is a specifically mentioned vehicle. Transfer is always built in as this way to solve treatment disputes. So the real type of futility dispute for which a new special legal mechanism would be useful is the dispute in which you can't transfer the patient. Here, I think it's worth mentioning that there is a case right next door to New York, in New Jersey, the *Betancourt v. Trinitas Hospital* case. Basically, the patient is actively dying, has all sorts of multi-organ failure and all sorts of problems. The providers thought it was inappropriate and cruel to continue to treat the patient. But the trial court ordered them to continue to treat. "Notwithstanding what you think is medically inappropriate, you must treat." That ruling worries health care providers in New Jersey, because they were unable to use their medical judgment. Hopefully, there will be guidance from the Appellate Court in New Jersey. This may actually be one of the first U.S. appellate opinions that actually gives some much needed guidance as to the rights of the providers and surrogates in these sorts of situations.

OUELLETTE: We could talk about these topics for a long time, but at this point, we are out of time. We need to conclude what I think has been a really interesting conversation. I had hoped we would have time to discuss New York's new Medical Orders for Life Sustaining Treatment (MOLST) law,¹⁹ which created a process for creating a single document that functions as a medical order covering a patient's wishes for CPR and other life-sustaining treatment. The MOLST is effective and transportable in all health care settings. Unfortunately we don't have time to discuss the impact of the MOLST or its importance in health care planning. Nonetheless, I hope our readers will educate themselves about the MOLST, which can be a very effective tool for end-of-life planning. I thank you all for participating today.

Endnotes

1. S.3164-A (2009)(S. Duane et al.)(passed by the Senate July 16, 2009); A.7729-C (2009)(A. Gottfried et al.) (in Codes).
2. See *In re Westchester County Medical Center* (O'Connor), 72 N.Y.2d 517 (1988).
3. New York State Task Force on Life and the Law, *When Others Must Choose: Deciding for Patients Without Capacity* (1992).
4. See NY Surrogate's Court Procedure Act § 1750-b (Health Care Decisions Act for Mentally Retarded Persons); 14 NYCRR § 633.11 (medical treatment for residents of OMRDD facilities; 14 N.Y.C.R.R. §§ 27.9, 527.8 (medical treatment decisions for residents of OMH facilities).
5. Surrogate Court Procedure Act § 1750-b.
6. As of the publication date, the FHCDA had been passed by the State Senate, but was still in the Codes Committee in the State Assembly.
7. Thaddeus M. Pope & Ellen A. Waldman, *Mediation at the End-of-Life: Getting Beyond the Limits of the Talking Cure*, 23 Ohio St. J. on Disp. Resol. 143-94 (2007).
8. *In re Livadas*, No. 080370/30 (S. Ct., Monroe Co. Apr. 28, 2008); G. Craig, *Court Denies Extension of Stay in Livadas Case*, Democrat & Chronicle, Aug. 20, 2008).
9. M. Handelman & B. Parke, *The Beneficial Role of a Judicial Process When "Everything" Is Too Much*, 11(4) Healthcare Q. 46 (Winter 2008).
10. Thaddeus M. Pope, *Legal Briefing: Medical Futility and Assisted Suicide*, 20(3) 274-86 J. Clinical Ethics (2009).
11. Jeffrey P. Burns & Robert D. Truog, *Futility: A Concept in Evolution*, 132 Chest 1987 (2007); Robert D. Truog, *Tackling Futility in Texas*, 357 New Eng. J. Med. 1558 (2007).
12. Thaddeus M. Pope, *Surrogate Selection: an Increasingly Viable, but Limited, Solution to Intractable Futility Disputes*, 3 St. Louis J. Health L. & Pol'y (forthcoming 2010).
13. Opinion of the Attorney General No. 2003-F1. Available on line at www.oag.state.ny.us/bureaus/appeals_opinions/opinions/2003/formal/2003_f1.pdf.
14. Thaddeus M. Pope, *Medical Futility Statutes: No Safe Harbor to Unilaterally Refuse Life-Sustaining Treatment*, 75 Tenn. L. Rev. 1 (2007).
15. Leigh Hopra, "Baby Dies After Hospital Removes Breathing Tube," Houston Chronicle, March 16, 2005.
16. Sylvio Moreno, *Case Puts Texas Futile-Treatment Law Under a Microscope*, Washington Post, April 11, 2007.
17. *Alvarado v. New York City Health & Hosps. Corp.*, 145 Misc.2d 687 (Sup. Ct., N.Y. Co. 1989); *Long Island Jewish Med. Ctr. (Doe)*, 168 Misc.2d 576, 641 N.Y.S.2d 989 (S. Ct., Queens Co. 1996).
18. *Long Island Jewish Med. Ctr. (Doe)*, supra n. 17.
19. N.Y. Public Health Law § 29 77 (13) (McKinney's 2009).

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