RS 160: Live at NECSS -- Jacob Appel on, "Tackling bioethical dilemmas"

Julia: Welcome to the Rationally Speaking podcast where we explore the borderlands between reason and nonsense. I'm your host, Julia Galef. I'm here with a couple hundred other people at the Northeast Conference on Science and Skepticism. Say hi, guys.

I have a fantastic guest for you. He is actually a return guest from 4 years ago at the 2012 NECSS. His name is Jacob Appel. He is a bioethicist -- but he is so much more than that. He is also a psychiatrist. He teaches at Mt. Sinai Medical Center and practices both at Mt. Sinai and Beth Israel. He's a lawyer with a JD from Harvard Law School. He's also an award-winning novelist, essayist and playwright. He is absurdly over educated. Jacob, welcome back to NECSS.

Jacob: Thank you. My fear was you were going to say that you were reason and I was nonsense. In this case, good advice!

Julia: Jacob is currently working on a manuscript for a new book, provisionally titled Harder Choices. It explores 101 challenging bioethical dilemmas that are taken in part from your own professional experience, and carefully anonymized. And in part from real stories from the headlines. Not that your own stories aren't real -- but publicly real stories from recent headlines.

I've been reading this manuscript. It was what gave me the idea to invite Jacob back to Nexus and they're really harrowing ethical dilemmas. Geez. I was playing this game with myself while I was reading. The game was: How much money would I be willing to pay to not have to decide that question? I was broke halfway through the book. That gives you a little sense of it. That's what we're going to talk about today. Harrowing bioethical dilemmas.

And zooming out a bit more, I hope to get into the principles, the philosophical heuristics that a bioethicist uses to try to settle questions like those. At the end, we're going to set aside a generous amount of time for Q&A. In the back of your mind as we're talking, you can be thinking about what bioethical questions you want to pose to Jacob as he's trapped here on stage at the end of the show.

Let's dive in. I think the first thing we should talk about is what a bioethicist even is. What is your job description? What's the role that you play?

Jacob: That's a great question. I should add by the way, the title of the book is not coincidental. The theory for Harder Choices is that many people out there will think it's actually Hard Choices, Hillary Clinton's best-selling book and buy it by mistake.

It captures what bioethicists do -- we may do 2 things. One, in the hospital setting -- and I've done this in the past, I actually don't do this at the moment -- bioethicists help adjudicate or guide patients, clinicians, family members in coming to ethical choices about individual patients. I should add, much of that is not telling people what to do or even telling people what their options are. It's helping them have permission to do what they want to do anyway. On the other hand-

Julia: So like a consultant, a management consultant.

Jacob: A consultant in a way. I will add it's one of the few fields that gets easier and easier as you

gray beard. You can say, "I've been in this hospital for 52 years. I've never left even when my children were in labor and nobody like your spouse has ever left the hospital alive." It's a powerful thing to say. When I say, "I've been here for a day and a half but I don't think things look good," doesn't carry as much weight.

The other thing bioethicists do is they offer public guidance on challenging issues that the nexus of law, medicine and ethics to clinicians out in the field so they can follow some general rubric on what to do. They try to increase the education that people have in the general public about these issues.

Julia: Are you never at any point saying to doctors or to the hospital administrators, "I think this would be unethical, or, this is a more ethical choice?"

Jacob: I'm not on the Ethics Committee at my hospital but what the Ethics Committee does do is rarely but occasionally direct. Occasionally, they will say something like, and the Ethics Committee will consist of 20 different experts in ethics from different fields in the hospital. This social work ethicist, the nursing ethicist and they work by consensus. If all 20 of them say, "We strongly feel you should do this or you shouldn't do that," whether or not it's legally binding, it's dispositive because no doctor wants to be in court and say, "You know, I asked the top 20 ethicists at my hospital, through all the major fields what to do and they all agree that this was the right thing to do, so I did the opposite."

Julia: What's the training for being an ethicist like? Is it basically a sub field of philosophy and you're reading different philosophical theories of ethics?

Jacob: Remember that Peanuts cartoon, something like “Advice, 5 cents”? Basically, you show up.

Unlike many other fields where you need a license, where you need professional training, there is no royal road to bioethics. Historically, people were trained either in Philosophy or in religious studies. Increasingly, people who trained in clinical fields, either medicine or nursing or social work but much of the field is built on people who just developed their clinical expertise overtime. It comes from seeing a lot of cases, which is why unfortunately, out in the public, there are people who hang up their shingles on the internet as bioethicists, who have no experience with clinical patients, have no formal training in the field.

Sort of like being a journalist. Anybody can say they are one.

Julia: As I did, for years.

I'm curious about is there any degree of expertise, any explicit principles that a bioethicist can point to that makes his or her advice more than just, "This is my own intuition or my personal opinion?"

I think before we get into that, I want to get concrete for a while before we dive back into the abstract. Let's talk about some examples.

I think the one I want to start with is the question of how to decide what a reasonable request is from a patient. To give you an example, you can imagine a female patient saying, "Look, I'd just be a lot more comfortable if my doctor, especially my gynecologist was female." I think most people -- and I imagine most doctors or hospitals, I don't know for sure -- would consider that request reasonable. And if feasible, would try to honor it.

Conversely, you could imagine a patient who said, "You know, I just think women are inferior. I just would be more comfortable if my doctor was male." A Ku Klux Klan member who says, "I'm not comfortable having a black person operate on me. I need a white surgeon."

Again, I don't technically know what hospitals would do in those situations but I can imagine that feeling less reasonable, feeling like a request that doesn't deserve our indulgence essentially. But these are just my rough sense of what our society considers reasonable essentially or what feels reasonable to me. I'm curious if there's any criteria that you can actually point to as a bioethicist to settle cases like that.

Jacob: There's a wide contingent with these cases.

Julia: Sure.

Jacob: Demonstrates why it's very hard on the one hand to have a concrete policy or even set principles. … Because you could say as a white Klansman, "I would like a white Christian doctor to treat me." That strikes most of us as fairly unreasonable. Or you could be an African-American criminal defendant who asked the court to appoint an African-American psychiatrist to do your forensic evaluation, because a white doctor just can't understand what I've been through. A lot of us would think that's more reasonable. Yet designing a rule that applies in one circumstance and not the other is extraordinarily difficult.

Julia: Yeah.

Jacob: The other example I used is you might be a male out there who wants a male urologist because he doesn't want women touching his private parts. Something you might think reasonable. Or you could want a male urologist because we all know that “men cut straighter.” Which is not true by the way, the hospital does not-

Julia: We're just going to cut that quote out and put it on the website.

Jacob: I figured as much. What the hospital does not want to do is to be in the position of figuring out which one you are. Yet, to me that's just in a meaningful way, that's exactly what we have to do. Therefore, if you have a policy in advance, you can ensure some rough sense of justice but inevitably… Procrustes, the Greek innkeeper with one size bed. If you were too short, he stretched you. If you were too long, he'd cut off your feet? The hospital doesn't want to find itself doing that either.

Julia: Right. One category of cases in which I feel like there is kind of an explicit rule -- maybe not officially, but in practice -- is that if a request is made for religious reasons, at least if it's a

well-established classical religion and not some smaller fringe or new religion, then it's much more likely to be honored.

Let's take that juxtaposition you gave of 2 people wanting a male urologist but for very different reasons. If you had a patient saying, "I'm an Orthodox Jewish male and I don't want a woman to be my doctor." My guess, correct me if I'm wrong, is that would be more likely to be honored than if a man said, "I'm a bigot and I don't want a female doctor," for that reason. Is there any codified policy to that or people are just more sympathetic for religious justifications?

Jacob: There are laws and series of court cases that protect the rights of religious minorities. Even there, you've demonstrated the challenge of this because if we announce that as the policy, if you're an Orthodox Jew, you can request a male doctor but if you're a bigot, you can't. Lots of bigots are going to say they're Orthodox Jews and we're going to be right back where we started.

Julia: Is that theoretical or is there any evidence of that happening?

Jacob: It's only theoretical because we haven't announced the policy strictly.

Julia: I see.

Jacob: One of the more complex aspects of this though is sometimes, we do look into the reasons that patients make their religious choice. I'll offer you 2 kinds of examples. One would be a Jehovah's Witness who turns down blood transfusions. Jehovah's Witnesses, even though there is some flexibility today, historically turned down blood transfusions because they believe that you were denied a place in heaven if you accepted one. There is no modern medical answer to the question of whether or not you were damned in the afterlife if you accept the blood transfusion. Jehovah's Witnesses will tell you, "I understand if I don't get one, I'm going to die." Exactly what you or I would say. It's sort of like Orthodox Jews don't eat lobster. You can tell them that lobster tastes good. That's not the point.

In contrast, Christian scientists turn down medication. Let's say antibiotics for pneumonia. Because they believe that antibiotics interfere with their proof to God that they believe in Him and they pray for a cure. Now hopefully, you and certainly I believe that antibiotics do cure pneumonia. There is a factual, empirical medical answer to that.

Those 2 cases aren't always dealt with the same. In the first scenario, we almost always let an adult choose. Increasingly, in the second area, we [don't] let adults choose. That's been a longer path. And then there are groups like the Attleboro cult in Massachusetts. They prefer to be called the Attleboro sect. It doesn't believe in the 5 pillars of modernity.

Julia: What are the 5 pillars of modernity?

Jacob: I'm not well versed in the Attleboro sect… I believe they include entertainment, education, banking, health care and something else very important to you and me.

Julia: I get the gist. Yeah.

Jacob: They don't wear eyeglasses if they can't see. They don't accept dentures. They won't set a broken limb. They've been around for 30 or 40 years. They have about 90 million members. Do they qualify as a religious group we should respect? Are they a fringe cult that can't make a sound decision?

Julia: Right. I guess I can see a justification for prioritizing, for giving more credence, more weight to the religious preferences of established religions as opposed to newer religions. If only because if there are no such criteria, no such discrimination, then anyone could just express whatever preferences they want and say, "That's my religion. I've named it Julia-ism, and now you have to respect it."

Do you think beyond somewhat extreme cases, there is justification for discriminating between older religions, and newer religions? Or larger religions versus smaller religions?

Jacob: I have one more component we should not lose sight of. It's how strong will you have to have this belief? The patient who comes to the hospital and is 85 years old says, "You know, I have a new boyfriend. He's a Jehovah's Witness, so I am, too." The daughter comes forward and says, "My mother was a Methodist until last Thursday."

It's the old jello test. You've all made jello with children. Your grandmother puts the cold water in the refrigerator and what's the first thing you do 30 seconds later? You go in there and open the refrigerator door and put your finger in. At what point does the jello transform from colored water into jello? I know this is a skeptics convention but if you believe in miracles, that is a miracle! At what point do you “gel” into a religious non-conformist?

In general, we do respect the decisions of religious minorities, but we use criteria not that different from allowing other people to make decisions. It's simply an added benefit. If you have a long tradition of supporting a particular group or a particular religious community, that can help bolster our claim that what you're making is rational in the context of your own life.

Julia: Got it. Got it. More on the subject of this intersection between religion or culture and medical choices. I'd be curious to hear what you think of whether parents should be allowed to select for a trait in their child, or make a medical choice for their child that society as a whole might consider to be to the child's detriment, harmful to the child. But to that family, to their culture, that's a valid cultural choice.

For example, choosing to have a deaf child, which could either result from choosing, selecting for an embryo that is deaf or declining any treatment to cure a child's deafness. And maybe those are treated differently but in either case, I imagine the fact that deafness is claimed to be a cultural choice, has to play a role, right?

Jacob: There is a third way, too, that we should not lose sight of. I want to enumerate all 3.

Julia: … Please don't say “making the child deaf.”

Jacob: Yes, absolutely.

Julia: That feels so different.

Jacob: We're all supposed to be rational people here. What is the difference between when you have a pool of embryos you can choose from, choosing the deaf ones to implant -- or when your child is born, let's say the day before it's born or when it's just about to hear for the first time, asking a well-trained physician to change its internal ear structure so it can't hear anymore. Either way, you've got a deaf kid.

Now unless you believe in the [soul of] hearing people and deaf people, there is not much practical difference.

Julia: I agree that it's hard to come up with a principled justification to justify why causing harm is no different than failing to prevent harm, for example. But in practice, we do seem to have a moral intuition that those are very different. I imagine that even if we can't say that's objectively correct, if we pull that pin out, a lot of other things collapse in our moral-

Jacob: If you assume that deafness is a harm -- which I'm not endorsing, by the way, but if you assume that-

Julia: Right. I'm not. I'm just saying --

Jacob: Yeah. By choosing that particular embryo, you're causing a harm in a very tangible way.

Julia: The comparison is harder because with a child who already exists, you can compare the counterfactual. If we hadn't done this thing, then this particular identified person would have hearing versus not have hearing.

If we're choosing an embryo, then you're comparing 2 people who -- you can’t say that **this** embryo would have had hearing if I had made a different choice.

Jacob: The British Fertility Board pointed out there's a pocketful of embryos who could hear they could have chosen. They need to really see the difference, which is why they didn't allow ... Paula and Tom [Leaky], by the way, were a British high profile couple who were deaf. They would have had a deaf daughter. They wanted to go forward with this... To the British authorities, there wasn't very much difference between their choice and actually just deafening a hearing newborn.

Julia: It totally seems like most people would have a different moral intuition. Clap your hands if those seem different to you! [Moderate clapping]

Jacob: They do for most people. When you ask them to enumerate it, it gets much more difficult for them.

Julia: Interesting. Well, actually this might be a good time to ask another question that I had, which is: You may be familiar with these 2 different systems of thinking or systems of decision making. System 1, which is our intuitive, emotional, instinctive way of thinking versus System 2, which is our reflective, analytical, cool headed system of thinking.

There's been a fair amount of debate over ... In some cases where there's an objective right answer, you can show System 1 tends to get that wrong. Questions about probabilities, System 1 tends to get often times get wrong, because we didn't really evolve to handle comparisons between .1 or .001% chance of something. Questions of scope, System 1 tends to get wrong.

But with ethical questions you can't just show, "Hey, System 1 is unreliable in this case." It's a more open question whether your System 1 or your System 2 judgments should be given priority basically.

A philosophical thought experiment I know we've talked about in the podcast before is the trolley problem, where there's this trolley barreling down the track, and there are 5 people who are tied up on the tracks. Or, kids playing on the tracks, say.

You can do nothing and let the train hit those 5 children and kill them or you have the option to push a man off a bridge -- or in some cases, pull a switch that causes him to fall onto the tracks. He's large enough that he will stop the train. Of course, he'll die in the process, but that will save the 5 children.

Experimentally, experimental philosophers and psychologists have found that when people are thinking more with their System 1, either because that's more the kind of person they are or because there's been an intervention that's put them more in a System 1 state of mind… They're much more unwilling to sacrifice the man to save the 5 children.

Because it's an upsetting thought. It feels intuitively wrong to be essentially killing someone. But when people are thinking more with their System 2, they're much more willing to sacrifice the 1 person to save the lives of the 5 because they can just calculate – objectively, better to save 5 lives than 1 life.

Some people, I think Joshua Green, a psychologist who's done many of these experiments, will say, "Well, you know, the fact that our System 2 gives this utilitarian judgment is a defense of utilitarianism. Because our System 2 is the careful thinking one."

I'm not so sure I agree with that reasoning. I'm not so sure it's obvious the System 2 answer is the correct one there. Maybe I sympathize with it more but I don't see how I would defend that as objectively correct.

My question is, to what extent do you think these intuitive System 1 judgments should play a role? I'm sure they must descriptively play a role in bioethics. How much do you think they *should* play a role?

Jacob: The most important thing that I've learned is to stay far away from trolleys, which solves a

lot of the problems. But let's say you live in San Francisco and that's not an option.

Julia: Yeah.

Jacob: I think what's most important is less when we use our System 1 and when we use our System 2, than knowing when we're using each one. Often, I'm absolutely fine if somebody wants to make a completely irrational decision, as long as they say to me, "Well, doc. I know my decision makes absolutely no sense but I'm going to do it anyway because I have to live with it." Rather than someone explaining to me in a very logical but utterly convoluted way why they're making a decision that is fundamentally irrational.

Julia: Got it. You see your role as the bioethicist in those situations to just make the person acknowledge what the trade off is that they're making, and then if they want to make that trade off, they can do so. As long as it's conscious.

Jacob: Within certain parameters. There are certain situations where I can intuit that the patient is making an irrational decision, and knows they are, without them having to tell me. The end stage cancer patient who is in denial, I don't need to put their toes to the coals to get them to say to me, "I'm really going to die." Because we both understand without discussing. But barring cases like that, I just want people to acknowledge which system they're using.

Julia: Yeah. Okay. Let's switch tacks a little bit.

There is this principle, which I didn't invent but I've been popularizing. It's called the Copenhagen interpretation of ethics. Essentially, it states that as soon as you interact in any way with a situation, you acquire some moral responsibility for it. If there's a drought in some geographical region, and you fly out there and you start selling bottles of water to people, a lot of people will look at you and say, "God. That's reprehensible. Why don't you *give* the water to these poor people who are going to die without it? Why are you demanding money for the water?"

Yet of course, there's millions of other people who never even went to the country nor said anything about it, and no one is criticizing them for not giving bottles of water to people who need it. They're criticizing the people who interacted with the situation in some way.

I bring this up because there are a couple of interesting case studies in your manuscript that I thought were examples of the Copenhagen interpretation of ethics. I'm just curious if you agree.

One of them is the problem of doing studies that involve withholding some treatment that we know works from people who are sick and need treatment. Let's say we have a pill called Pill A. We know that this works pretty well at treating some disease. But there's a new pill, Pill B, that we think might work better -- or maybe it's cheaper and if it works, that would be much better to be able to give Pill B to people.

Ethically, we can't justify splitting people into groups and giving some of them Pill A and some of them Pill B. Because the people getting Pill B, even if they don't know who they

are, we're withholding treatment from them, essentially.

Some doctors have gone to third world countries where poor people don't have access to any of these pills and are suffering from these diseases, and done the studies there. Arguably, no one in those countries is being harmed. Some of them are clearly being helped, and some of them may or may not be helped depending on whether Pill B actually works. They're not worse off than they would have been.

But my understanding is this is a pretty controversial, pretty criticized practice, to use different ethical standards in another country. What is your opinion on those cases? Do you think I'm right in my diagnosis?

Jacob: The ethical incentive this creates is if you never leave your apartment then you'll be perfectly ethical.

Presumably, there are some thresholds you have to reach in engaging, before you really take responsibility for something. But I think that's a really good example. There is a difference between you flying through Uganda and having a layover in the airport, you engaged in their country, and therefore, becoming responsible for all of its poverty.

… Versus you running a complex clinical trial testing treatments for AIDS in Uganda. Some of which work and some of which don't work as well, where you're taking a much larger degree of responsibility. You're a trained professional and you're wearing the badge of a fancy Western university.

There's probably a continuum of responsibility. At the extremes you're talking about, I agree with the principle.

I think increasingly, there's a consensus in this country that you can't do that. Martha Angelo when she was editor of the New England Internal Medicine, decided not to print the results of these studies. Most journals now won't do them.

Julia: Can you elaborate on why you agree with that? What's your response to the argument that you're not making anyone worse off than they would have been, and are in fact helping some people?

Jacob: Let me offer you an analogy that might be helpful. Let's just say there is a famine in Country X. You decide you're going to solve that famine by adopting a child from that country and bringing the kid back to our country and feeding him well. All of us will view that as a good thing in the context.

Instead, you adopt 10 children and you feed them a subsistence diet because that's what you can afford in your home country. Most of you would feel very uncomfortable doing that. You take them out of a horrifically abusive home and you only beat them on Thursdays. We wouldn't accept that. Why is it okay if we do it across the border?

Julia: That is intuitively compelling. I just want a principle.

Jacob: As we established last time, sometimes there are things where it's very hard to establish a principle. Yet intuitively, we can recreate pretty good societal consensus and the right way to do them. We know it's hard to come up with a principle but we still don't do them.

Julia: All right. All right. That's fine. Moving on.

Jacob: You ask the questions!

Julia: All right. Another phenomenon that I noticed and that I picked up on a few times in the examples in your book, is that there's this trade off between being a utilitarian versus avoiding causing any harm, following the maxim “first do no harm”.

One example at the personal doctor level that I think that happens society wide as well is a person coming to a doctor and saying, "Look, I really want to amputate my limb. It's not medically necessary but I feel like a strong psychological urge to do it." Or a different example, parents coming to a doctor and saying, "Look, we really want to have our daughter circumcised because that's our culture, but we prefer to do it here in a nice, clean, competent medical setting than back in the tribe where we live. Will you help us?"

In both cases, there's the implication -- either they explicitly stated the intention or the implication -- that the person, if they don't get a doctor to perform it for them, will just do it on their own. That it would be more painful and likely to be risky.

One can say the doctor in that case is doing the best thing overall by saying, "Okay. If the surgery is going to happen, at least let me make it happen safely." Or you can say, "No. The doctor should not be performing medically unnecessary amputations and circumcisions."

Jacob: I think what you're really doing in a lot of these cases is balancing the welfare of the individual and their outlying request with the welfare of society as a whole, in terms of establishing principles that medicine operates by, establishing a rule of law, establishing consistency.

The patient in the hospital is almost always a one time participant, where usually the doctor in contrast is often a repeated player. As a repeated player, you can never give the patient all the care they need, because you always have competing goals or competing values from other patients. This is simply an extreme example of that. Where you're weighing the goals of the society against what might actually make this particular patient better off in the context of their lives.

Julia: Can you elaborate on how making that choice to agree to the patient's request would impact society, or the doctors' other roles?

Jacob: Sure. In this particular case, let's take the example of the female genital cutting because I think it's more complex. This girl may end up being taken back to Africa, end up being cut with an unsterile knife, end up having far more severe medical complications -- or not getting the procedure, might end up unmarriageable in her local community, end up a social outcast and die of poverty. All of which are very possible.

We have to weigh that against the implications of setting up a system that allows other people to accept this as a social norm. Because then more people may come forward, and efforts to eradicate the procedure elsewhere may become more complex. The belief that doctors won't do something overtly harmful may be undermined in our society.

A much more basic example of this is you can just think of a scenario where you have a patient who comes to your office and is a school bus driver. He drinks like a fish. What you really want to do is engage him in care over several months. In doing so, you'll get to know him better. You'll be able to help him get alcohol treatment. But you put all these little kids in the bus, in the process, in danger.

On the other hand, if you simply report him to the authorities, you may keep him from killing those little kids. But what is he going to do? He's going to tell all of his other hard drinking bus driver friends, "I told my doctor this private information and she called the authorities." In the long run, we may end up with more drunk people driving school buses and not fewer. Hard calculus to make.

Julia: The idea is that a lot of these things that seem to be the utilitarian choice locally are actually not, when you zoom out and broaden the scope of your calculus.

Jacob: Exactly.

Julia: All right. How about, okay. This was a tough one that I outwardly groaned at when I read it. There's a very contagious disease going around. Contagious via the air not through blood, for example. There are people who are carriers of this disease. They themselves are not, their health is not at risk, but they can transfer it to other people. We don't yet have a cure for this disease. Our choices are between basically quarantining the person against their will, so that they don't infect other healthy people, and spread the epidemic. Or letting them go free and risking that they're going to make the epidemic much worse.

I forgot how much I was going to pay to not have to make that choice but it was a lot. What's your take?

Jacob: The New York City Department of Health is glad to make that choice for you. They've taken it off your hands.

The power case to point to is Mary Mallon, who is majorly known as Typhoid Mary. We spent a good number of years enforcing the quarantine in North Brother Island, in the river across the way with very, very little outside contact. Because as the poem goes, "Everywhere that Mary went, typhoid was sure to follow." For Mary, that is a significant hardship, but for the parents who lost kids to typhoid, that was also a significant hardship.

I will use that case to point out that we now know that there were lots of other people in New York City carrying typhoid at the same time. They just weren’t poor, female Irish-American immigrants.

We want to make sure when we're doing this, first, if we have the Science right, and that

we're not singling out one subset of many carriers and placing the burden on them. Once we do that, then I think we have to really step back and ask that “if we were designing a world” question with a veil of ignorance...

Julia: Are you implying that there is a clear answer to that question that we would want to take that-

Jacob: I think if we took a vote -- and I say this with empirical evidence, because when I’m giving bioethics lectures, I actually posed a number of these questions. My sense is that in the general public of people who pay $150 for a bioethics lecture, about 80 to 90% would put Typhoid Mary on the island. Your audience, I don't know. They're more skeptical. Maybe they don't trust me.

Julia: It's interesting. There was this meme going around Facebook recently, at least it was in my section of Facebook. And it showed the trolley problem with a nice visual illustration. It said, "Most people think that when you're answering the trolley problem, you're this guy who's making the choice of whether to pull the lever and drop the man from the bridge. Actually, the right way to approach this is, you don't know which guy you are. You could be one of those guys on the tracks. You could be the fat man --"

Oh -- in the classic problem, he's supposed to be fat because that's how he can stop the train. But it's not a very nice framing of the problem!

Anyway, I don't know if that version of the problem has been given to people. I imagine the results would be pretty different if you're behind a veil of ignorance and you don't know which of the people in the scenario are you are.

Jacob: The opposite then becomes more difficult... If I tell you, next time the UPS guy delivers a package, we can tie him down. Cut him up and deliver his organs to 6 different people and save their lives. Virtually none of you will join me with a knife.

Julia: Right.

Jacob: I hope.

Julia: Okay. I'll ask you one more question, then I'd like to hear if there are any dilemmas that you think are particularly challenging or interesting.

I think many people here might have read the book, Nudge, by Cass Sunstein -- and this has been reported elsewhere. Basically, the finding that was so striking from that book was that when you switch the system of organ donation in a country from being opt in to being opt out, you get a huge skyrocketing of the percentage of people signed up for organ donation. Basically, people still have the right to choose not to be organ donors. They just have to actually opt out of process.

I think the number was in the 90's, 90-something percent of people in countries that switched to the opt out system are organ donors, which is a huge good for the medical

system.

To me, this seemed like a clear win. It's just great. You don't have to take away any freedom from people or any autonomy. You can vastly increase the supply of organs. Wonderful. Done deal. No question.

But in your book, you made it seem not quite that simple. Why is that?

Jacob: I will point that you can have a system using opt out that gets 100% donation. You know how you do it? You make the system opt out and you don't tell anyone. It's very effective.

But that's part of the problem. We live in a country where more people can name the 7 dwarfs than the justice system and Supreme Court. A handful of people out of 100 can name the Vice-President. All these alarming figures.

To actually have a system where you fully inform everybody is a daunting task. What often happens is the cultural religious communities most likely not to want to donate organs or want to opt out are those at least in the network to know what the rules are. Beyond that, you run the risk of people losing faith in the organ donation system.

I think this also comes up where there are networks -- I believe Project Renewal is the most prominent one, that largely recruits organs from Jewish donors and seeks Jewish recipients.

In theory, you might say that's a great thing. They're increasing the number of organs available. If they give a kidney to a Jewish recipient on the list, somebody who is not Jewish will be able to get an organ.

That might be true. We don't know for sure, because the danger is, people will say, "Ah, they give organs to Jewish people and not non-Jews. I don't want to be part of that system. I don't trust them." I'm not saying that's true, but I'm saying the integrity of the system in its perception is crucial to making it work.

Julia: Right.

At this point, I want to invite you to tell us about any of the particularly interesting dilemmas you've personally had to face.

Jacob: I'll share a couple of issues I'm interested in.

One is how to use public resources that have private implications. A classic example of this is the question of whether trace amounts of Lithium should be added to the drinking water. A number of psychiatrists have written about this. It turns out that a certain percentage of the drinking water in this country already has Lithium in it naturally. And the areas where it does seem to have a substantially lower suicide rate. This is the finding that is replicated in Greece, in Turkey, in Great Britain, in Japan. The science is pretty good.

Now the first question you should ask is, would it be ethical to divert water from those

areas where it's in the water supply, the areas where it's not? If you embrace that theory, then why wouldn't it be just as ethical to actually add synthetic Lithium, in the same way we add fluoride to the drinking water?

I will tell you, if you raise this question, even without offering a definitive answer, you will get more hate mail than you could possibly imagine. I can tell you that-

Julia: This is not theoretical?

Jacob: This is not theoretical.

Julia: I see.

Jacob: That is a more abstract question for you to think about.

A more practical question -- I do a lot of my work in health care resources. Historically, the great questions from bioethics were scenarios where a patient or a patient's family wanted to stop care. Society, religious or cultural reasons wanted to enforce care upon them. You can think, Caroline Quinn, Nancy Rosanne, Terri Schiavo.

We have now turned that on its head. Now increasingly, the cases are those where the family is saying desperately, "We want more care." The hospital or society is saying, "You've exhausted your version of care. In the new priority system, nobody is worth $5- $10 million of health care in one shot. You're out of luck."

It's easy by the way, relatively easy, when the patient is comatose or in a vegetative state. But you have patients like Slim Watson for example, who was a prison guard in North Carolina in 2000. Written up at length in the Wall Street Journal. He could walk around the hospital, bright and cheerful, entertaining the pediatric patients, and was in the prime of health. Except he needed a drug that caused roughly $5 million a month. Is anybody worth $5 million a month?

The answer is, "It is if you are the patient, and not if you're not."

Julia: Do you have any understanding of why that balance shifted so dramatically? Why patients now want to continue care beyond what the doctors want to provide?

Jacob: I think there are 2 factors at work. One, the recently older cases have evaporated. The courts have increasingly made the rules clearer. We've adopted a far more autonomy oriented approach. Letting patients and families make their own decisions when it comes to ending care...

However, a combination of technology on the one hand and high profile cases on the other have led people to believe in, I hate to say it, but miracles of their own health care status. For example, we all know that the life expectancy with diseases like motor neuron disease, ALS or abdominal mesothelioma is relatively short. If you live 5 good years, that is rather impressive.

Nobody takes that to heart. They look at Stephen Hawking and they say, "I can be him."

They look at Stephen Jay Gould, 20 plus years with abdominal mesothelioma and say, "That's me." Even if there are only 5 cases out there. Therefore, a large portion of people in essence believe that just because nobody else in their condition has ever left the hospital doesn't mean their grandfather won't.

Julia: Right. I've actually been re-watching Scrubs lately. It's some of my comfort food TV. There was a scene that made me gasp, in which Dr. Cox -- who is grating, some might say abusive, to his interns, but he is supposed to be this brilliant and righteous doctor. He says to JD, the protagonist, "Statistics don't mean anything to the individual."

I'm sorry. The way he says it, it's clear he means if you're an individual trying to decide whether to use a risky surgery or a risky procedure, ignore the statistics because you're an individual and statistics don't apply to you or something like that.

This actually reminds me of the problem that you're talking about a few minutes ago in which, yes. We can officially tell people that they can opt out of the organ donation system, but a lot of people are ignorant and just won't know. And can it be considered that we've then really given them a fair choice?

I wonder for any risky procedure, or patients who are participating in a study that has some risks to them, a statistical risk.. If we know that people have a hard time understanding statistics, and will assume that their case will be special and it won't happen to them, can we really say that we've got informed consent?

Jacob: Informed consent I would argue is a misnomer. The best we're asking for is reasonable disclosure. We're asking the doctors here what a reasonable patient would want to hear.

Whether the patient is really informed, even though we pay lip service to it, is highly doubtful. Because if you only look through it once and you don't have that context, your decision is going to be a largely intuitive one, maybe with a sprinkling of data. If you went through it a thousand times like the doctor, you might make a very different choice, but that's never an option.

Julia: … I'd be interested to hear if there are any principles or heuristics that you've developed in thinking through your bioethics cases. You don't have to defend them as objectively correct, or use them all the time in a hard and fast way.

Jacob: I think your audience may not like this that much, but I believe there's some data on buying houses. I'm going to butcher the details, but if you buy a house because it's close to the train station and it's a flat driveway, you won't have to shovel, it and lots of other rational reasons… you're less likely to be happy with it in the long run than if you buy the house because you just liked it.

I think that's somewhat translatable to many bioethics decisions. You get a feel for the family. You get a feel for the family or what the patient wants from the scenario and then

you help them get to where they want to end up, which is a far more artistic, subtle intuitive process, rather than simply outlining for them 2 very different rational paradigms.

Often if they are a rationally oriented person and choose the most rational paradigm, it may not be the right paradigm for them. The difference between bioethics as it applies in hospitals and many other areas of society is there are a lot of different right answers depending on who you are.

Julia: What about at the society level? A decision whether to add Lithium to the water supply, or not or whether to allow research in third world countries that we wouldn't allow here, that sort of thing. When you're not trying to midwife someone else's decision, what kind of principles do you use?

Jacob: There are 2 principles I'd like to talk about. One is my own, one is somebody else's.

One, when deciding what society should let people do, I find it very valuable to ask not what would I do with it and think of a situation, but whether I can conceive of any reasonable person out there making that particular decision. If it's a decision that I can't think of any reasonable person making or find any pathway to get to a rational decision, and then I'm far more comfortable forgoing people's right to do it.

Julia: Any examples come to mind?

Jacob: Yeah. I can offer you a practical example from a hospital setting. From the hospital setting, occasionally, you'll have somebody come in and they will turn down an emergency life saving surgery. Let's say the new treatment for appendectomy. They will say, "I have a good reason why but I don't want to give it to you."

Those are the rare cases where we really override individual autonomy. It's very hard – not for me to conceive of a reason that people wouldn't want to have an emergency appendectomy, but of a reason that people wouldn't want to have an emergency appendectomy knowing they're going to die *but also wouldn't want to share their reasoning with me*. I just can't get there.

You can try to think of cases. There are hypothetical constructs you can come up with. It's very hard to come up with them.

Julia: Do you have any guess about what's actually happened? Assuming you're correct and they don't have a good reason, that they also have a good reason for keeping a secret. What do you think is happening?

Jacob: Usually, I think they're probably either misinformed or they're imbalanced, which accounts for a lot of the ... Nobody can say, "I'm misinformed and imbalanced that's why I made this decision."

Julia: My reason for keeping a secret is I was embarrassed that I'm imbalanced, and so I-

Jacob: Basically.

Julia: Right.

Jacob: The second principle I think is valuable is actually not me. It's Lester Thurow. He explains why we got into the challenging situation with health care right now in this country.

He says, "Because Americans are divided by 2 different principles. On the one hand, by nature, we're libertarian. We believe that if there's some treatment or intervention out there that is available, that anybody who has the resources for it should be able to buy it." Some European countries don't let you do that, which is why those patients come here. Here, a high end treatment, Bill Gates can go out and get it. We don't feel comfortable saying that.

But we're also egalitarian by nature. If we let one wealthy person have it, then we want to find a way to let everybody have it. A rising tide raises all boats even if the boats shouldn't rise. Suddenly, everybody is buying this something that may not be societally cost effective.

The result of that is we end up helping visible victims at the expense of invisible victims. Because people see Slim Watson and his $5 million and they say, "I don't want him to die." They don't see too many people who didn't get flu shots, or the 500,000 people who didn't get mammograms, because of Slim Watson's $5 million worth of care.

Julia: Right. Is there anything that your opinion has evolved on in the time that you've been studying bioethics? Cases you've changed your mind on, or things you're more hesitant to justify now than you were before?

Jacob: I think as I do this more and more, I feel more and more comfortable with letting people make their own decisions even when I think they're profoundly bad ones.

Julia: Yeah.

Jacob: I feel more inclined. I think with adults, we often let people do that. With children, we become more and more conservative. Our current theory, which is the Supreme Court case, the principle Massachusetts justice Gottlieb said, paraphrasing, "It's acceptable for people to make martyrs of themselves but not to make martyrs of their children. We should let their children live life where they can make their own decisions."

Up to a point, I embrace that. But I think it's crucial we don't lose sight of the fact that those parents and that child have to live with the consequences far more than I do, going back to the hospital and seeing the next patient.

Julia: My sense -- I don't know if I got the sense from your book or just from talking to you before -- was that in the trade off between respecting a patient or a family's autonomy versus enforcing the solution that seems like clearly the best solution to you, the doctor, the bioethicist, that you weigh more the autonomy side of that equation than maybe a typical bioethicist. Is that right?

Jacob: I think that's a fair assessment. I think a lot of that comes from seeing the consequences of when you get it wrong and also seeing the consequences in my own life. The Copenhagen interpretation, intervening in other's people's world.

I also have my own world where I'm a relative to people and I've heard what the hospital bioethicist has to say. My thinking was not, "Oh, great. Here is this eminent gris trying to give me his wisdom." My thought was, "This is my relative. Not yours. What the heck do you know?" I imagine the people I deal with feel the same way, and I try not to lose sight of that.

Julia: Do you think society in general has gotten those choices wrong enough in the past that we should significantly underweight our competence when we impose a solution?

Jacob: I think there is no doubt that historically, Science, Medicine had gotten a lot more wrong than they got it right. Maybe the balance is tipping in the other direction but it's easy to forget our misses.

My favorite one is, I teach the medical students this. In the 1920's, there were 2 treatments for an acute heart attack in New York City. Most people would prescribe 6 months of bed rest. This cardiologist… at the height of prohibition, prescribed beer, and would write beer prescriptions.

Everybody laughs. But it turns out the people who got beer did a lot better. Not because beer cured heart disease. I'm not telling you that. Don't go home and have your elderly drink beer. But the people who got bed rest without anticoagulants died in large number of blood clots. The beer was utterly neutral.

That affected tens of thousands of people.

Julia: Was that his point or did he just really think beer was a cure and he got lucky?

Jacob: No. He just thought drinking was good for us. But he stumbled upon the right answer. He also prescribed them to small pox and diphtheria and-

Julia: Man with a hammer.

Jacob: Yeah. Occasionally, he hits a nail.

Julia: I have an out of left field question I've been meaning to ask you. I have the sense that the field of bioethics has a surprisingly large Christian influence to it. I say that because I've seen a lot of Christian bioethicists writing essays on the internet, but also because there's certain principles that I see cited in bioethics, like in bioethics journals, that have a Christian flavor to me.

Like the idea that tampering with the natural state of the human experience or the human body is an affront to nature, or it's a crime against human dignity or something like that. There was also the President's Council in Bioethics, appointed I think by George W. Bush,

that had a bunch of Christians on it. Maybe the proportion of Christians in bioethics is not high relative to the country, but I think the baseline I'm using is philosophers, who seem much less Christian than bioethicists.

I'm wondering if that, am I picking up on a real thing? And if so, why is that true?

Jacob: I think historically, many of the people in bioethics starting when there was the bioethics revolution of the 60's and 70's, were what we would call liberal Christian thinkers. Many of the underlying principles of bioethics… really do stem from people who thought that what doctors were doing may have been well intentioned but was blind to the larger picture of making the world a better place.

I think many of those people, although religiously motivated, developed a set of principles that largely embrace secular values like autonomy.

What we see now is a much more conservative Christian interest, is really a backlash against what has become the ethical norm in medicine. I can tell you that there are many people I know who are very religious who are ethicists, but very few of them have the kinds of, I would say, dogmatic or ideological agendas that people on George Bush's bioethics commission had.

They are not representative of the norm, I don't think, in this country.

Julia: If a bioethicist is religious, does that influence the advice that he gives to patients? Maybe he's not saying, "Well, as a Christian, I think you should do X." But urging patients to do something because that seems right to him, and the reason that it seems right to him is his Christianity.

Jacob: I think our role is to guide people and not to grab people and drag them. I think I would be a fool to say that bioethicists, certainly in the hospital setting, don't have biases. I think it's important to be aware of these biases with yourself.

And they can actually prove very helpful. You can say to the patient who is a fundamentalist Christian. "I can't speak to your tradition but I'm an Orthodox Jew and this is what I believe. This may help you to some degree." You can also just try to [speak to] them neutrally. But it would be a mistake I think to tell them, "I don't have any religious bias whatsoever, and this is the right answer."

Julia: Yeah. I think we're almost ready to go into question and answer. I don't know who's responsible for handing out the mic. Someone? Yeah, excellent. I'm going to ask one more question and then while Jacob is answering, we can have people come up and ask questions. Yes? Okay. I don't know how this is going to work. Hopefully, it will work.

My last question for you, Jacob, is whether there are any technologies that are on the horizon now, or that have the potential to be on the horizon maybe 5 or 10 years from now, that you think are going to pose interesting new bioethical issues. Or that maybe you're personally concerned, about that you think may well be used unethically.

Jacob: I thought you were going to ask if I did Bar mitzvahs. I was all excited.

I think an issue I'm not concerned about, by the way, is human cloning, which gets lots of press. There's some data that suggest that the majority of time the Congress has spent discussing bioethics issues over the last 20 years was about human cloning. If you do surveys of audiences in the country -- and I ask this all the time. How many of you would like to be cloned? Nobody ever raises their hand.

I think the most interesting issue for me is going to be the development of law and politics around pre parent babies.

Some of you may know there is now a process for extracting nuclei from one egg cell and infusing it to the cytoplasm of another egg cell, fertilizing with a third sperm, and then in theory, you can place that embryo on a 4th surrogate mother to bring the child to term. You can end up with 3 genetic parents, and a 4th biological parent. How society goes through who is the official parent, who has custody over the child, who makes decisions, is one we had a lot of differing answers in different places. It's one where there's really not an intuitive consensus.

Julia: Excellent. I think we have our line. Let's start over here.

Audience member 1: Short question. I'm an epidemiologist for a large pharma company. Drug traces are quite large. Hep C is changing the market a lot. It costs 100 grand a year to get cured of Hep C. The alternative might be liver cancer, a really expensive disease that you have to cure alternatively. Also, the pipeline. If you have an expensive drug, then you can invest in a lot more clinical trials for other drugs. Question for you is, what do you see as the ideal ethical approach? What criteria would you use to evaluate the optimal drug traces for drugs? Thank you.

Julia: Short question indeed.

Jacob: Short question. I'm a short bioethicist so it works perfectly.

I think the intuitive answer is not the right one. The intuitive answer would be to send in a rational system and figure out exactly where it becomes cost effective for society in relation to other expenses, seeing how large a pool we have of health care and assuming that pool is somewhat immutable.

I think you probably want to have some margin there for what people as a whole versus a society, especially if we can't agree rationally on the right answer. The analogy I would draw is: the Oregon Health System has a fairly rational system where they don't pay for treatment for end of life diseases, and certain end of life diagnoses with a low prognosis of living, less than 6 months. I think they set that at 5%.

It turns out, rationally, you could actually take that period substantially lower, and they could put it substantially higher, and reallocate the health care dollars and try to put a more rational answer.

But intuitively, none of us would feel comfortable with telling somebody with a 20% chance of living in a year and a half, you can't get chemotherapy. In the same way, I think we want to figure out what the rational calculus is and figure out what the society wishes, and come up with some balance between the two.

That unfortunately is why we have elected officials, to figure out that balance.

Audience member 2: Hi. I'm a primary care physician who treats patients with opiates with narcotics. Just recently as 5 years ago, that's what we were taught to do. Now all of a sudden, we are the problem. There's a great pressure on us especially starting in 2017, where we will be retrained and we will have strong disincentives to prescribe. What obligation do I have to my patient who is on chronic narcotics? There's no diversion by this patient at all. I'm trying to get them down to a low a dose as possible, but yet, they do not want to come off because they fear their quality of life is going to be sacrificed. Versus society at large, versus the state, who will actually fine me in 2017 if T's are not crossed and I's are not dotted.

To me, it's a very complex situation and one way, I sometimes I feel a sense of loss of what I'm supposed to do.

Jacob: I think that's a great question. It's an issue you're going to hear a lot more about. It's a great example of hard cases making bad law, in a sense, because there are outliers. There are doctors who abuse the system. There are patients who abuse the system, and we have a national epidemic.

We decided to rule that it's both over inclusive and under inclusive. I think the individuals who are going to suffer from it are people exactly as you've said, who have already been established in one system and are asked to switch to another. If I designed the system, I would much have preferred a system that allowed some kind of grandfathering in, and much slower over time adjustment to a new way of doing things.

I understand that governments don't like doing things that way, not just here but in many other areas but I agree. It's deeply problematic.

Audience member 3: Hi. First of all, I'm a fat guy who lives in San Francisco with a trolley line literally outside my front living room. You're scaring the hell out of me.

But my question has to do with a lot of the dilemmas that you post come down to the difficulty we have choosing the best of several bad options. Given the choice between a good option and bad option, kind of everybody agrees. Let's take the good option. When we have to choose between the least bad of several bad options, we seem to have a barrier. We want a good option out there somewhere and we're frustrated that it's not there. Is this a problem with our cognition or some other way that we think about hard dilemmas like this?

Jacob: Can I tell a joke? I tell you it's a joke but you might not know...

Two professors retire and go to Yellowstone. They're about to take their first walk. The first morning, the guide says to them, "You know, gentlemen, I have to warn you. There could be bears in the woods." It's a legal disclaimer. First professor says, "Fine. We'll risk the bears." Second professor goes back to his cabin and gets his running shorts. The first professor says, "Are you out of your mind? You can't outrun a bear." The second professor says, "Of course, not but now I can outrun you."

That is how unfortunately, many decisions are made in health care and it's a framing technique I think most of us use.

When we give people two undesirable options, by nature, they twist one of those options into a desirable one. I think you hit the nail on the head. I don't have an answer about how we can convince people to see both of those as unpalatable because there is no greater motivating factor for most people than hope.

Audience member 4: This is about altruistic kidney donation. I suppose you're aware that there is a website which matches people who want to donate kidneys, and the donor picks out the person she wants to do that. I just really feel this is not the way to go but I was wondering how that's seen in bioethics.

Jacob: I will add that there've also been advertising campaigns. A number of years ago in Texas, there were billboards all over the state.

The question of whether you could allocate your cadaver organ to someone else -- If this increased the supply of organs, I would not be opposed to it. I would still have some problem with it in the sense that you're going to have a justice issue of allocating the resources.

I think the greater question to which we have no empirical data is does this actually increase the supply of organs? Would those people donate anyway if they didn't have the choice? Are other people being steered away from the process because they perceive it as unfair?

Until we know the answers to those questions, I agree with the questioner. This is deeply problematic. Unfortunately, there are complex social and financial incentives, visible versus invisible victims. Once somebody shows up at the hospital and says, "I'm willing to give a kidney. Here's my friend I met online going to accept the kidney." It's very hard for a Nephrologist to say, "We wish you the best of luck but not here."

Audience member 5: I think many philosophers… [define something like a function by which ethical evaluations can be made]. An alternative to this is virtue ethics, which views ethics as one of many traits by which a living thing can flourish or not flourish. Does this have any practical place in making practical decisions in a medical setting?

Jacob: Virtue ethics was basically all we practiced for many, many years, though we didn't call it that. We asked the senior doctor at the hospital what he thought the right thing to do was…

Unfortunately, more often than not, when we look back in those cases, we got it deeply, deeply wrong. I think there is a role for it in the global picture of coming up with an answer. I don't think it affords us increasingly an answer to many of these questions. In part because making any of these ethical decisions now is complicated by the depth of knowledge we need to have to make one of the decisions. We need not just a sense of ethics but also a sense of technology. Increasingly, finding people who have both of them is extraordinarily hard to do.

Julia: We have time for one more question.

Audience member 6: Thank you. You touched earlier on the respect offered to religion in terms of patients' choices. Could you touch a little bit on the respect we should offer to religion in terms of the organizations, religiously affiliated hospitals, insurance companies and so forth? I know there are some campaigns to insist that such facilities disclosed to all patients what limitations there may be on their care ahead of time, because obviously, many of these facilities provide care to a vast numbers of people who do not subscribe to that particular religion.

Jacob: I will offer two thoughts on what is a very complex field, that I've actually written a fair amount in, and I'm glad to talk to people additionally or they can email me their questions.

I think on the one hand, we want to ensure a system where people at a minimum know what is valuable to them at any particular facility they get care. On the other hand, we also want to make sure that everybody out there in a reasonable way can get the kind of care they want. Within those parameters, I also feel it's important if we can attain that, to allow people who have different views to practice medicine.

… The example I would use is if you're a Christian fertility clinic in California -- this is a real case – and you won't inseminate lesbians. If you tell people this upfront, and the remaining other clinics in the area will do it, it's not particularly problematic. It's different from baking a birthday cake in my mind, it's not an intimate long term relationship.

But if you're the only fertility clinic in the area, or you don't tell people that you do it in advance, that becomes much more problematic.

Achieving that in practice is challenging but I think there are ways to do it.

Julia: All right. We are just about out of time. Thank you so much, Jacob for returning to Nexus and to Rationally Speaking. Let's all give Jacob a big hand.

Jacob: Thank you. Thank you.

Julia: As always, this concludes another episode of Rationally Speaking. Join us next time for more explorations on the borderlands between reason and nonsense.