

Recent book: "A Theory of Bioethics"

Joseph Millum is the author of a new book about a new theory for bioethics. The volume offers a carefully argued, compelling theory of bioethics while eliciting practical implications for a wide array of issues including medical assistance-in-dying, the right to health care, abortion, animal research, and the definition of death. The authors' dual value theory features mid-level principles, a distinctive model of moral status, a subjective account of well-being, and a cosmopolitan view of global justice. In addition to ethical theory, the book investigates the nature of harm and autonomous action, personal identity theory, and the "non-identity problem" associated with many procreative decisions.



Featured Speaker:

Joseph Millum, Ph.D., M.Sc.

Joseph Millum is a bioethicist with the Clinical Center Department of Bioethics and the Fogarty International Center at the US National Institutes of Health. He studied philosophy at Edinburgh University and the University of Toronto, and economics at Johns Hopkins University. His research focuses on the rights and responsibilities of parents, the ethics of international research, informed consent, and priority setting for health care and research. His books include *Global Justice and Bioethics* (2012), *The Moral Foundations of Parenthood* (2018), *Global Health Priority-Setting: Beyond Cost-Effectiveness* (2020), and *A Theory of Bioethics* (2021).

Transcription:

VO: Welcome to the Peds Ethics Podcast, where we talk to leaders in pediatric bioethics about a hot topic or current controversy. Here's your host, John Lantos, from the Children's Mercy Bioethics Center in Kansas City.

Dr. John Lantos: Hi, everybody. Welcome back. This is John Lantos with the Pediatric Ethics Podcast coming to you from Children's Mercy Hospital in Kansas City, Missouri. We are thrilled to have with us today, Joseph Millum, who's a bioethicist at the Clinical Center of the National Institutes of Health and at the Fogarty International Center where he provides ethics consultation and educational support. He's a prolific author. His books include *Global Justice and Bioethics*, *The Moral Foundations of Parenthood*, *Global Health Priority-Setting: Beyond Cost-Effectiveness* and the book we're going to talk about today just out from Cambridge University Press, *A Theory of Bioethics*. Thanks for joining us, Joe.

Dr. Joseph Millum: Thanks very much for having me, John.

Dr. John Lantos: And I understand that the views you're about to express here are all your own, and you're not representing the United States government, the NIH, the Fogarty Center, or anybody but yourself.

Dr. Joseph Millum: That is correct. Yes, I'm representing my views and hopefully also the views of my co-author, David DeGrazia.

Dr. John Lantos: Perfect. I am so curious. The two of you wrote a new theory of bioethics. What motivated you to do that? Why do you think we need another book on theories of bioethics?

Dr. Joseph Millum: Yeah, fair question. We were motivated to do it because we perceived a need for a book that was able to give approachable, but relatively high-level theoretical approach to bioethics. And one that could bring in a number of concepts that we think are very relevant to bioethics, but are not focused on that much in existing. So for example, we spend quite a bit of time talking about the nature of well-being, the nature of harm, what it is that I'm talking about, the non-identity problem, and these are all very philosophical issues, but they also do have implications for bioethics. And we wanted to create a theory that was philosophically rigorous, was broader in scope than we thought other theories were. But also that like those other theories, we could show why what we were saying theoretically mattered practically.

Dr. John Lantos: Let's talk a little bit about the idea of well-being that you developed in the book. You give primacy to that as a moral value and the moral obligation to promote well-being. That sounds a lot like beneficence in either the Belmont framework or Beauchamp and Childress. How is your idea of well-being different?

Dr. Joseph Millum: Yeah. And I wouldn't say that everything that we're doing is uncharted territory, right? We've learned a great deal as I think most people working in bioethics in Anglophone countries have from Beauchamp and Childress. We learned a great deal from the Belmont report, which I think is a beautifully written piece of work and one that succinctly expresses a number of the ideas that we are trying to explicate at much greater length.

We do have different views, I think, about what well-being is, and we have different views about what it is that individual, the institutions have to do in order to promote it and in order to avoid causing harm, right? Promoting well-being and causing harm being flip sides of the same coin. So for example, we think that individual obligations to promote well-being are pretty substantial. Both in what's called the imperfect duty of beneficence. That is the duty to take some efforts to promote well-being where you have some discretion about how you're going to go about doing that, right? You have some discretion about how you are going to take stock of your life so that you make other people's lives better. But also in the context of rescue where we think there are what philosophers would call perfect obligations, ones where there are no options to provide benefits to others when you can do so at a relatively low cost yourself. And we think that those end up giving pretty stringent obligations to promote well-being, not just stringent obligations to avoid harm.

Dr. John Lantos: So the obligation to promote well-being then sort of bleeds into, if you will, discussions about justice and what obligations doctors or healthcare systems have to provide beneficial medical care to patients. Do you want to speak a little bit about how you tie those together and how your ideas of justice may differ from prior theories of bioethics?

Dr. Joseph Millum: Yeah, absolutely. So we have a theory of justice that we think is at relatively generic liberal egalitarianism. So we think unchosen differences between individuals are unjust and those are ones that ought to be corrected. Now, we think it's relatively generic that it's one that many liberal philosophers would agree with. Nevertheless, it has pretty radical implications for how countries like the US ought to be set up. And we think it supports the right to healthcare for everyone. And we have a

view about international justice, which is one that basically takes the same core idea that our theory of justice for the state has this idea that unchosen differences between individuals is unjust and applies it to the international context. Unchosen differences between individuals born and living in different countries are also unjust.

But let me come down to the question about how that relates to beneficence, which is that in a context where you had a just state, that is where the state was giving everyone everything that they were owed. Most of us would have relatively minimal duties of beneficence. The use of tax dollars would be to provide people with what they were owed, including healthcare. And it would only be very exceptional cases where we as individuals were put in a position where we had to rescue someone, right? Typically, we would have people who are trained to do that basically.

Dr. John Lantos: So essentially, we'd meet our beneficence obligations through paying our taxes.

Dr. Joseph Millum: Through paying our taxes and through having jobs and roles that provided the help to people that they needed, so sufficient clinicians, firefighters, et cetera, et cetera. But what we actually have is a pretty unjust state where many people don't have access to safe housing, adequate nutrition, healthcare when they need it. And the question is what do we as individuals have an obligation to do when we're in the actual unjust circumstances?

Dr. John Lantos: So I'm going to push you on to implications of that. One, about doctors in the United States where we do not have a universal healthcare system and their obligations and then a little bit, if we have time, on global obligations, particularly around COVID vaccines or COVID treatments.

But let's start with docs in the US. You make an argument that I think a lot of doctors might find difficult or troubling. You say it's true that if healthcare systems were reformed, individual physicians would not have to volunteer their time to treat poor patients. It's also true that if all physicians volunteered their time, then each would only have a small contribution to make, but neither of these conditions is met in the actual world. And you then go on to argue that each individual physician therefore has a duty to do more than they ideally would be required to do, that seems like that's asking a lot.

Dr. Joseph Millum: Yeah, it may potentially be asking a lot. The fact that we live in a very unjust society and that many people do not do what they would ideally means that those people who are committed to acting well have to do much more than they otherwise would. There have been a very interesting debate on this in the context of obligation to the global poor, which I think is really relevant to the question of what physicians in the US owe to people who are indigent or people who don't have health insurance.

That debate started off with this idea that by donating money to effective charity, it will be possible to save many lives overseas, so like buying antimalarial bed nets could save children's lives in malaria endemic countries. But it looked like for those people who would be willing to donate to do that, they could donate all of their money before they solved the problem. And a philosopher called Liam Murphy argued this is unfair. What you're basically saying is, as you were suggesting with physicians in the US, what you're basically saying is those people who are willing to do that duty have to do much more than they would have to do if everyone was doing their duty and you shouldn't ask people to do more than they would do under what he called conditions of full compliance, where everyone does what they

should.

Dr. John Lantos: That's sort of the idea, that no good deed goes unpunished. I mean, if you are a good person, more is asked of you.

Dr. Joseph Millum: Absolutely. But virtue is its own reward, right? So that all works out fine. There's a very under-read article by a guy called Michael Ridge where he points out there is an unfairness. If you, Dr. Lantos, are doing what you want to do, but the others around you are not, you can complain to them that they're treating you unfairly. They're not contributing in their fair share. Or if I'm contributing to charities and other people are not, I can say you're not doing your fair share. But then the question is who should bear the burden of the fact that these individuals are not doing what they should, right? Is it you, the well-off clinician who has extra resources that they could provide? Or is it the extremely disadvantaged people that we're originally talking about benefiting? And the idea is that it would be more unfair to put the burdens of non-compliance on the people who are most disadvantaged than to put the burdens of non-compliance on people like you or I, who might be comparatively better off.

Dr. John Lantos: So how does this play out then in the context of COVID and preventive or curative treatment?

Dr. Joseph Millum: Yeah. So the COVID pandemic has really been eye-opening I think for a lot of people in terms of both how healthcare system have functioned or failed to function and the ways in which they've turned out to be unjust in terms of who has access to what. But there's been a lot of discussion about how we ought to allocate either scarce treatments, so remdesivir very early on and now treatments like monoclonal antibodies and about vaccines. A lot of debate within the US about how these should be allocated within the US and then also debates internationally.

And so at the moment, basically any adult or anyone over 12, I think, who wants a vaccine, is going to be able to get one. And that's the situation we're in at the moment. But in many countries, that's just not true. In many poor countries, most people are not able to access vaccines, even people who are very high risk for severe COVID if they were to become infected or people who are working on the frontline, healthcare workers and so on. So there's an ethical question about when richer countries, European countries or the US ought to share supplies of effective vaccines.

Now, from my point of view, I think now obviously we should, because we're at a point where in richer countries, the people who are at high risk or either have or could be vaccinated with the supplies that we have. There is an interesting ethical question about at what point one ought to start sharing, right? And if you treat everyone in the world equally, then that point is probably pretty early on in the pandemic, that is the people who are most vulnerable everywhere in the world should be getting equal priority.

Dr. John Lantos: And that certainly has not and is not happening.

Dr. Joseph Millum: No. And practically and politically, one understands why it didn't happen. Nevertheless, we could have hoped for vaccine sharing to happen earlier than it has and to have been done on a more equitable basis.

Dr. John Lantos: Absolutely. Let me shift gears. In the last few minutes, we have here one of the other controversial aspects of your theory of bioethics. Your opinions about animal research. You write that the traditional presumption in favor of conducting animal studies before proceeding to clinical trials involving human subjects is morally backward. There should be a presumption against involving sentient animals in research. Is that what you would see as a sort of universal or global ban, that there should be no animal research involving sentience animal subjects?

Dr. Joseph Millum: No, I don't think we believe that there should be a global ban. We do think that the way that animal research currently is set up, there is relatively little regard given for the well-being of those animals. Now, there are some rules that apply. There are some requirements in terms of how you treat animals in terms of their well-being, but there is a general assumption that it's acceptable to breed animals with debilitating conditions, to expose animals to noxious chemicals, to kill them at whatever point is convenient and experiment and so on. And we think that any sentient being, any being that has a welfare matters morally. And so anytime you're going to do something like that with a non-human animal, it has to be justified. It has to be justified in terms of some sort of benefits in terms...

Dr. John Lantos: To the animal?

Dr. Joseph Millum: Not to the animal. No. You mentioned earlier on that theory talks a lot about the value of well-being. It's a dual value theory. We care about well-being and we care about respect for rights. And we think that creatures like most humans who have narrative identities are creatures that have rights. Now, it wouldn't be permissible for example to conduct extremely harmful research on a human who wasn't able to give consent for the sake of others. But for nonhuman animals that are cognitively less sophisticated, possibly rodents, we don't think that they have the protection of rights, but nevertheless, that welfare matters. So you can justify causing harm to those animals provided that the benefits to other individuals outweigh them.

And so we argue both that presumption actually sets quite a high bar, right? Because you may know that you're going to inflict severe suffering on several hundred rodents. But the benefits down the line are highly speculative, right? The translation from doing basic research in rodents to actually helping humans is pretty speculative. And we think that there are lots of reasons to question the presumption that the use of animal subjects is generally essential for finding out information that's going to benefit humans.

So if you think about it just in terms of how we would assess risks and benefits of research generally, we think the risks should be justified by the benefits of the research. That's a standard sort of tentative research ethics, but we also think that risks should be minimized consistent with achieving the scientific objectives. And we think that for a lot of animal research, those two conditions are not met. That doesn't mean that it's never met.

Dr. John Lantos: If you had to guess what percentage of animal research would fall below your bar how much of it would you find morally impermissible?

Dr. Joseph Millum: I could not make that guess because I do not have a good grasp of the full landscape. I would refer you to David, to his recent book, Principles of Animal Research Ethics, which he just published, I think, a year ago with Tom Beauchamp. And that would give you a much more

extensive analysis of the data, but also the principle that they think should underlie doing research with animals.

Dr. John Lantos: Alrighty. Well, I wish we had more time. This was a great teaser and I hope our listeners get the idea that this book takes a lot of important ideas and raises some provocative, challenging questions about ethical opinions attitudes and theories that you might take for granted. And after reading this, you might find yourself feeling a little moral disquiet.

The book is put out by Cambridge University press and is available free online at Cambridge's website. You can download a copy. You can read it online. It's beautifully written. So I encourage everybody to take a look at this new theory of bioethics. We're talking with Joe Millum, who's one of the co-authors with David DeGrazia. He's a bioethicist at the Clinical Center of the NIH and at the Fogarty International Center. Thanks so much for joining us today.

Dr. Joseph Millum: Thanks ever so much for having me, John. Pretty great talking with you.

Dr. John Lantos: And I'm John Lantos. This is the Pediatric Ethics Podcast from Children's Mercy Hospital in Kansas City.

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