Interview with Arthur Caplan

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INTRODUCTION

It is a difficult task to succinctly describe the professional accomplishments of Arthur Caplan, PhD. For the uninitiated, Dr. Caplan is perhaps the most prominent voice in the conversation between bioethicists and the general public, as well as being a prolific writer and academic. He is currently the Drs. William F. and Virginia Connolly Mitty Professor of Bioethics at NYU Langone Medical Center and NYU School of Medicine, having founded the Division of Bioethics there in 2012. Additionally, he co-founded the NYU Sports and Society Program, where he currently serves as Dean, and heads the ethics program for NYU's Global Institute for Public Health. Prior to joining NYU, he created the Center for Bioethics and Department of Medical Ethics at the University of Pennsylvania Perelman School of Medicine, serving as the Sidney D. Caplan Professor of Bioethics. Dr. Caplan is a Hastings Center fellow, also holding fellowships at The New York Academy of Medicine, the College of Physicians of Philadelphia, the American Association for the Advancement of Science, and the American College of Legal Medicine. He received the lifetime achievement award of the American Society of Bioethics and Humanities in 2016.

Dr. Caplan's experience is not at all limited to the academic realm: he has served on numerous advisory counsels at the national and international level, and is an ethics advisor for organizations tackling issues from synthetic biology to world health to compassionate care. Dr. Caplan has been awarded the McGovern Medal of the American Medical Writers Association, the Franklin Award from the City of Philadelphia, the Patricia Price Browne Prize in Biomedical Ethics, the Public Service Award from the National Science Foundation, and the Rare Impact Award from the National Organization for Rare Disorders; he also holds seven honorary degrees.

Kaitlynd Hiller and Rachel Bloom, both M.S. Bioethics graduates of Columbia University, had the opportunity to meet with Dr. Caplan last winter to conduct a candid exploration of his career as a bioethicist. Their conversation touched on moments in Dr. Caplan's personal history that planted the seeds for his future professional involvement with bioethics, discussing his evolving views over time. Reflecting on his own impact to the field, Dr. Caplan leaves us with wisdom for bioethicists beginning their career in the public sphere. A lightly-edited transcript can be found below.

INTERVIEW

INITIAL INTEREST IN BIOETHICS

Rachel: Can you tell us anecdotally how you became interested in bioethics as a field?

Caplan: There is sort of a deep psychoanalytic kind of reason and then more of a recent causation kind of reason. When I was little I had polio and I was in the hospital for a long time. I was six -- a little, little kid -- in Boston where I grew up. At that time, it was so long ago, your parents couldn't stay over. In fact, your parents didn't visit that much. I think I saw them three times a week and I liked my parents, at least at that time. I didn't see my dog, ever, for nine months. They managed to get me my homework, which didn't seem great, but the main things were kids were dying, they wouldn't tell us the truth. We knew they were dying because they looked so bad. They said they went home. They didn't really listen to complaints about, you know, why're the visiting hours are so strict. Why can't my friends come and see me? That sort of stuff. It definitely got me thinking about what we would now call ethics issues, although they certainly didn't call them that back then, they were just issues. And even as a little, little kid, it was bothersome. So I'm sure that got my interest going. Later, I was going to go to med school. I was a premed at Brandeis, outside of Boston, and I went to Columbia [for medical school] briefly and saw all kinds of interesting ethical things going on. I started to talk to the deans and other people about when we could explore this stuff. And they said, "Well you just talk about it with your attending." Which you were never going to do, ever, because they would consider that an insult and they would have you washing bedpans for weeks. So –

Rachel: Questioning the ethicality of their actions?

Caplan: Or even say, explain it. I didn't know about the field of bioethics, although it was getting underway. We're talking mid '70s, so the Hastings Center and the Kennedy Institute already existed; I just didn't know it. And I went down to the Columbia Philosophy Department and said I would like to get a Master's Degree in Ethics and take time off to do that and they said, "Well, first of all, we don't have a Master's Degree in Ethics, because we only take PhD students. And second of all, we aren't interested in" -- I think the phrase was "the ethics of plumbers." Meaning doctors. And I said, "OK. I'll sign up for it anyway." And so I went into the PhD program, but I thought I'm just going to dropout and then get a Master's Degree and it'll be all good. Not really interested in philosophy, but the issues were fun, other students were smart, and I liked it. So I thought I'm going to do the degree and then go back, but I never really went back. I went back as the medical ethics guy and sort of started the program that you guys are now in, except by a long, twisty course.

WHAT IS BIOETHICS?

Rachel: I was just going to comment, I think a lot of people are thinking about bioethical issues without necessarily knowing the name to attach to it.

Caplan: Yes. I often say, "I do bioethics," and people are like, "What's that?" And then you say, "Well, you know, end of life care; Terri Schiavo; Jack Kevorkian; cloning; stem cells; genetic engineering." And they're just, "Oh. Oh. I get it." Yeah, absolutely true. You know, "Should we quarantine people, should we give people drugs without testing them?" They get that. They understand right away that there are good ethics issues there. Sometimes they're also a little afraid of "ethics," so you have to be careful how you use that word because ethics could also mean people who are going to church or you're going to yell at me for being a derelict, or whatever it is; people also confuse ethics with what I'll call politeness or manners.

PERSONAL INTEREST AND TRANSPLANTATION

Rachel: When you entered the field, were your goals more along the lines of drawing on your personal experiences, focused on patients having different, better experiences in the future?

Caplan: Well, despite the motivation of wanting it to be nicer for kids, that wasn't really what was driving me by the time I got into this. I was interested in the theory. And I began almost by writing about things like, what sort of concepts of health and disease should drive medicine? How do you define them? What are medicine's goals? What we now call philosophy of medicine, which I'm still interested in and I still write about; what is health, what is illness, what is disease-type stuff. But nobody ever seems to ask me about it – they just don't find it as interesting as, should the surrogate mother have to get an abortion if the commissioning couple wants her to? It's like, that gets them. "What is Health" is like, you know, call me when you figure it out. So it was more theoretical stuff.

But I began to get interested in this new area that was emerging of transplants. And it was sort of high tech and very risky and a lot of the people who got the first transplants died. And some hospitals actually prohibited people from doing transplants, they were so dangerous. And that just got my attention and then I began to wonder -- because I was still going to Columbia -- why weren't we doing more transplants? Because we had a lot of people with kidney failure and only a small dialysis unit to take care of them. And it turned out that one problem was there weren't enough organs. So that was a very practical problem and I said, "OK. You go and try and examine that, why aren't there more organs to transplant?" Because we had the capability, we just didn't have the parts. And that led me to still be interested in transplant ethics, you know, 30 years later. And I did some very practical things there, if you want to talk practical. We figured out the people at hospitals were not asking about organs when people died. You have to ask for them to get them, so I wrote up a law and got it through the New York State Legislature called Required Request, which was you had to ask when somebody died. They didn't have to give, but you at least had to ask them. And that became law in most states and then it became a hospital accreditation requirement, then it became part of Medicare funding eligibility. So, it's everywhere and people have to do it. Then I also realized that [institutions] weren't sharing organs. They weren't playing nicely with each other. They got an organ, if they couldn't use it, they threw it away, literally. So they would, like, say, "Well, if we can't use it at NYU, then we're not giving it to Columbia. They're our competition, so we're not going to send it there." So, eventually I hooked up with Al Gore, who was a Congressman from Tennessee and interested in medicine and science and technology, and we worked out with his staff the United Network for Organ Sharing. We built the system that became the distributor of organs and that was a lot of work; very interesting, and it stood the test of time.

So those were two very early experiences, practical bioethics, changing laws, sitting down in the real world and saying, "You're going to get a kidney and you're not. Here's why and these are the criteria and this is how we do it. And if you don't like it, you can complain, but these are the rules until we change them."

BIOETHICIST AS EXPERT

Rachel: How has your experience been shaped being a bioethicist, but not a healthcare professional? Have you found particular challenges from this?

Caplan: Yes. When I first started out, I was not only not a doc, but I was too young. So, going after somebody's ethics who's senior, who's a very established doc, is a real challenge. You have to be very political about it and very diplomatic about it. It's always been an issue in terms of making sure that you know enough medicine and science to be credible to the group you're talking to and I came as a premed and I did spend a lot of time at the Columbia Hospital, sort of a long internship. Most people assume I'm a doctor today because I sound the jargon and do the walk and in the transplant community, I'm like an honorary member of the International Transplant Society. I mean, I'm treated like a transplant doc and that's all been good and very helpful, but without acquiring that mastery of one of the sub-disciplines and knowing the jargon and knowing what's going on at the bedside, it would be very hard to be taken seriously, even to this day. So we tried to force students to spend at least a little time learning how the hospital functions, what people do, how it operates.

ISSUES IN BIOETHICS

Kaitlynd: What issues in bioethics today do you think are overemphasized or talked too much about? And which ones are not discussed enough, but are really important?

Caplan: The stuff I'm not interested in gets talked about too much and what I'm interested in doesn't get talked about enough. I would say there's a shift that will surprise you. There's a lot of interest in public health ethics overseas that gets talked about a little too much. There's plenty of public health problems here. You don't have to go overseas. Part of me gets a little irritated when somebody says, I'm going to go solve the problem of poor people in Sierra Leone, if there's a bunch of poor people in the Bronx. It's sort of like, can we do them first? It's easier to deal with people who won't talk back or are going to give you a hard time. I like public health ethics, but I don't think it all has to be in the poorest places on earth where the great white saviors arrive.

There's probably too much attention to some of the weird reproductive technology stuff, because it's rare. It doesn't impact that many people. I get the interest, it's just eternally fascinating, but it gets overemphasized.

Underutilized: nursing home ethics, rehab ethics, mental health. Last year I put out a reader on mental health ethics to try and get people interested in that area. The only time people seem interested in mental health ethics is when there's a mass shooting, otherwise they don't seem to care a whole lot. Chronic illness doesn't get a ton of attention. Acute stuff does. High tech gets a ton of attention and I pay attention to high tech and I pay attention to cutting edge, whether it's CRISPR or stem cells, but I try to be across the board with it. I think I've probably written two-thirds of the literature on rehab ethics, because I've written about six papers on it. You know, it's not a big area. I try to get people to pay attention, but it's not drama. It's sort of like – it was once said we should develop a cardboard box and put lights in it and tell people they had to stick their head in it and charge them a lot and say this is the Rehabitron. And then people would say, "Oh! We've got to pay attention to rehab. Should we pay for the Rehabitron?"

PAST IDEOLOGY

Kaitlynd: You've written extensively over many, many years – are there any positions that you took in past debates that you might disagree with today or go back on or change?

Caplan: Yes. I'll give you a current example: I was an early critic of Oregon's assisted suicide law. I thought it would get abused. I thought people would get coerced into selecting death. I thought people would have their families pressure them to not spend all their money. Empirically, it just didn't happen. I know people still say it does, but I try to look very hard and I don't see any evidence of coercion or forcing people or any discontent at all with the law. So I've switched and become a supporter, at least of terminal illness as a trigger to allowing people physician-assisted suicide.

I was a believer for a long time that if we switched from an opt-in system to get organs to an opt-out system that that would get us more organs. I'm not sure the evidence bears that out either. So I've slowly shifted -- it's not that I'm against presumed consent, but I don't think it's going to have the impact that I once dreamed of because families and doctors still behave the same whether it's opt-in or opt-out. They still go and ask the family, they just do, you know, when somebody dies. So I think you have to find ways to expand the donor pool. Maybe bring people who are dying to the ICU and put them on machines. If you don't expand the pool, whether you have a market or a presumed consent, I don't think it's going to matter much, and I used to.

It's also funny when you change your mind or shift, because people are often citing you on their side, so I'm like, "I'm not on that side anymore."

FUTURE ISSUES

Kaitlynd: What are the next issues you see yourself focusing on?

Caplan: I'm definitely starting to pay attention to germline genetic engineering. I've been long interested in genetics, was interested in gene therapy, and you didn't ask me this, but when Jesse Gelsinger died, that became a big crisis -- here's this young man and he dies and his father doesn't think the consent is very good and they're off protocol in terms of what they were doing in the study and it was a mess and so, trying to figure out: how do I respond to that as the house ethicist? I hadn't been at Penn that long, so I had to work through sort of thinking about what do you do when you get a sort of catastrophe in your own institution.

That early experience around genetics stuff, I didn't lose that. You probably know too that I've written an awful a lot about Nazi science and the Holocaust and how it shaped experimentation. Well, germline engineering, you know, when you're starting to edit hereditary traits, it gets us back to a place where a lot of scientists said we'll never go; we're not going to touch the germline, which I always thought was utter bullshit, because they didn't know how to do it, but now we do know how. So that theme there is very interesting for me.

It's pretty clear that rationing scarce resources is going to be a big issue for a variety of reasons; cost, aging population. This experiment with unapproved drugs is going to lead to a continuing interest on my part in how to allocate resources fairly. I'm very interested in research ethics issues and particularly things like what trial designs are the most ethical, depending on whether it's an emergency or just some boring hair growth remedy thing -- how do you design the trials? If informed consent -- written informed consent isn't working all that well, then what will? For profit IRBs are here. What's that going to look like? So I'm interested in all of that.

I would say still, because of the recent experience with Ebola and pandemic flu, I'm interested in the ethics of humanitarian emergencies, the ethics of what to do when there's a sort of a massive threat.

PEER IMPACT

Kaitlynd: Is there someone, a clinician or another academic, whose work has had an impact on your career?

Caplan: Oh yeah, many. I was lucky. I had pretty good mentors. In the Philosophy Department at Columbia, Ernest Nagel, a famous philosopher of science, definitely encouraged me. He didn't know what I was doing, but encouraged me and said, "You know, you're a good speaker, you can explain things well, you should think about more of a public role, not just wind up in the classroom or in the ivory tower like a philosopher." When I got to Columbia, there was a guy named Bernard Schoenberg, David Rothman, this guy I mentioned is the Bernard Schoenberg professor. Schoenberg was one of the guys who said, "Why don't you go down and see if you can get a Master's Degree in philosophy. I support you in your interest in medical ethics." He was supportive and he would offer good comments and tips how to deal with doctors and that sort of stuff. Dan Callahan and Will Gaylin at The Hastings Center were very influential for me because Dan was a good writer and he edited me to the extent that I can write clearly and well. Dan was the kind of person who would edit your lunch order; if you sent it to him and it had typos, he would fix them. So he was pretty committed. Will was an early pioneer in bioethics in the public. He did the first TV show on public television about bioethics. He would talk to journalists and I watched him and thought, I could do that, and I think that's important to do. And so he was useful that way. And there were others; there was a woman at Hastings named Ruth Macklin. You've probably run across Ruth -- so I was a junior graduate student at the Hastings, she was there as one of the first staff members, and I watched her make arguments and interact with people and I thought, ah, that's pretty cool. She was very friendly. I got to know her very well. And she was an influence in terms of seeing how you could argue and use persuasive argument to change people's minds about things.

FINDING A PUBLIC PLATFORM

Rachel: We had a question just asking about your general ubiquity in the mainstream media when it comes to issues of bioethics. You were mentioning your advisor said you shouldn't want to be a part of the ivory tower, so how did you come to find a public platform?

Caplan: Well, it's interesting. It was deliberate, not an accident. After watching Will do this back in the '80s at the Hastings Center, bioethics was still struggling to try and be legitimate, get grants, be in journals, not just bioethics journals, but get into the New England Journal, get into JAMA, places where routinely there are bioethics articles today. In fact, I don't put a lot of my articles into bioethics journals; I put them into medical journals because they have a bigger audience.

But it also seemed to me that if we were going to talk to patients and then have a practical impact, that wasn't going to work through the journals because it just doesn't. And the only way you can change policy, which I knew from my transplant experience, was to get the attention of politicians, and they watch the media. So the media becomes important as a vehicle to talk to patients, talk to politicians. So, I said, "You know, when I get the opportunities, I'm going to do this." I taught a couple of guest lectures in the Columbia School of Journalism Science class. Volunteered to do it with a guy I knew named Ken Goldstein. Then a couple of events like the Barney Clark Artificial Heart, the Loma Linda University baboon heart transplant came into public attention and I wrote some bad articles about them and sort of muscled my way forward and said, “You know, these are scientifically interesting, but they raise all kinds of important ethical issues. You should think about the ethics.” I did that with answering journalists’ calls when they came; no one else at Hastings wanted to do it, so I did it, or sometimes actually calling them up and saying, “You know, I read your story, but you don’t have a word in here about ethics and you should pay attention to the cost or the who gets it or the why are we doing this at all because it didn’t work on animals, so.” And then, as I said, there were big issue cases, Baby Doe, the fights about handicapped infants that were just sort of presenting themselves and I thought, these are natural teaching opportunities.

[To build a public platform], you have to be good at it. Most bioethicists are not. You got to be quick, witty, on point, succinct. These are not traits that capture a lot of bioethics. I quickly moved to starting to write my own stuff. You’ll see me doing op-eds all the time and I started doing a syndicated newspaper column back when I moved to Minnesota. It ran in like 150 papers, but then I had my own voice. So taking control and having a footprint where people started to say, I see this guy writing opinion pieces. I would try to keep my scholarship going so that people couldn’t dump on me as just a Carl Sagan or Steven Gould popularizer. So of all the people in bioethics, I believe it’s true that I’ve written more period papers than anybody.

That said, a) academics don’t like popularization; and b) they are envious of it. I can’t tell you the number of people who say, “Well, I don’t own a TV, so I don’t really care what you do.” But then they would say, “But I heard you on public radio or I saw you in the New York Times.”

Kaitlynd: Well not only would you get flak from people, but has anybody given you criticism about you being the sort of spokesperson for the bioethics community as a whole?

Caplan: Constantly. My attitude and my answer has always been, “Take what you get. You only get a minute thirty, so, you don’t want to do it, don’t do it. But if you think you’re going to build in seven distinctions in your 20-second sound bite, probably not doing that.” I hear some of the criticisms of, “Why are you the public face of bioethics?” Part of me says, “Because I know how to do it.” And that’s why. It’s pretty simple. They’ll go to people they think can do it. If I wasn’t good at it, they wouldn’t come back.

IMPACT ON THE FIELD

Rachel: If you may be so bold, what impact do you think your work has had on the field?

Caplan: Well, it’s funny in a couple of ways. In setting up bioethics programs at Minnesota, at Penn, and here [at NYU], that definitely has an impact because people watch the Penn program; a lot of people are training with me, so I can see the Stanford Bioethics Program is all people that were at Penn with me, junior people then, now they run it; Peter Ubel at Duke, David at Louisville. Upstate New York did a lot of programs that have spun out from my teaching, and I try pay attention to mentoring. I think it’s very important. I had good mentors; I want to be a good mentor. Part of my job is to make new scholars and new people for the field,it isn’t just to throw my name onto their papers or steal their research, which does go on and I don’t like it.

The field is known around policy circles and by at least some people around the world and I think I drove that. Nobody writes articles anymore on medicine science without paying attention to ethics. That wasn’t true when I started. It’s true now. They always have something. They feel guilty if they don’t say something about, you know, there's an ethical issue with whatever stupid new technology it is; the new thermometer. I think that's been good.

I think I perfected public policy in some useful ways. Transplant, absolutely. Built a way to get organs. Built a way to distribute them. Now working on this compact idea with J&J to distribute unapproved drugs. It's drawing on the transplant experience; I think that's going to work. I could cite four of five other policy places, but I definitely had a direct impact on change in terms of fixing a problem or trying to get something solved that wasn't solved and I like that. I think that's -- bioethics should do that. And it's funny because it's similar to when I first got into it. When somebody says, "Do you want to try and implement it?" We should say, "Yes." Not, "Gosh. I'm too afraid." Or, "I'm hiding now." Or, "Why don't you read my articles." Or something. So, yeah, in a lot of ways.

I fought stupid things like quarantining Ebola and sort of beat that to death. Helped patient groups a lot behind the scenes. I mean, I -- it's funny, it's like egomaniacal hour, but I helped set up the National Marrow Donor Program. Made sure we protected the donors and that sort of thing. Ran the Blood Safety Advisory Committee. Eventually got them to flip the ban on gay men donating blood, although it took 15 years, but finally got it.

I like to think I set a tone that is somewhat lighter than the usual dreary world of academia, which very much matters to me. I'm friendly with my critics for the most part. It takes a lot to get me to really jump down somebody's throat in an angry way, but I'm trying to say, you know, we can argue about these things. I could be wrong, but we can kind of enjoy the whole thing. We don't have to sort of, you know, treat ourselves like we're having an argument amongst the minor Greek Gods.

ADVICE TO BIOETHICS STUDENTS

Rachel: In the interest of broadening this field of which you're currently at the head, what advice would you give to people who want to take the issues they're learning about and make it more public?

Kaitlynd: To be part of the societal conversation about bioethics.

Caplan: Oh, I think I've wedged open the idea that there is a conversation. So that's out there to be used. Second, you've got to be scholarly to be credible. So there is no shortcut. You can't just go out there and say, I'm going to write op-eds all day on Twitter and share my views because eventually someone's going to say, what is this based on? There is relatively little that I comment on that I haven't written something about. You know, I write a lot, so, it gets me a big portfolio, but if you hang around long enough, pretty soon you've written about everything. But you've got to have that foundation. Decide what you can credibly comment on and stick to it.

Third, you've got to practice, which means write some of your own opinion pieces, try blogs, see what works and learn. Ask for feedback. Show stuff to your peers; what do you like about it? Show stuff to your mother; what do you like about it? You know, try it out. I do that. My dad and my mother are still big commentators on things I do. They hear me on public radio in Boston every week now and they feedback to me vigorously at 95 and 92.

I think it's also important to realize that people are not interested in the same thing that a bioethics colloquium would be interested in. They don't really want your reasons. They want to know what their options and alternatives are. So it's a little bit more translational in terms of what you're trying to achieve. Then if they ask, you supply them with arguments.

Lastly, you know, a lot of what I do, I take positions on lots of things and I'm not afraid to do that, but often all I'm trying to say is CRISPR [or another biomedical shift] is coming, it raises a whole slew of issues, and you ought to pay attention. That's what I call the prophetic mode. We try to look ahead and say, "This thing is going to make issues and here's what some of them I think are." And that's it. That's useful in the conversation; it isn't just having answers; it's sometimes raising questions in the Socratic way, if you want to think of Socrates in the marketplace. There's some of that that goes on and it's very important to be ahead of the game. I mean, we were talking about cloning 15 years before Dolly appeared. Stem cells, same thing. And that means being on top of science. So, you got to know where it's going so you can flag it in a timely manner.