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Ethical Issues Across the Primary Care Spectrum

Dr. Brian McDonough:

Welcome to Primary Care Today on ReachMD. I'm your host, Dr. Brian McDonough and with me today is Dr. Art Caplan. Arthur Caplan is well known internationally and certainly you may have seen him on any of the talk shows. He is an ethicist, a medical ethicist who talks about issues that, in fact many of us, and certainly in primary care, we have a whole bunch of them, and a lot of things we could talk about. Welcome to the program.

Dr. Arthur Caplan:

Hey, thank you for having me.

Dr. Brian McDonough:

Dr. Caplan, my first question and something that I know a lot of people are curious about is, genetics in medicine and we hear so much about how the primary care doctor is going to have a toolkit, where they're going to be able to take samples and find out what diseases a person is going to have down the road, and clearly we're starting to see some of this already, what is the impact of this and how do you see it, ethically and as far as primary care doctors doing the best for their patients?

Dr. Arthur Caplan:

Well, it's a great question, Brian, because I think it hasn't really burst in the primary care yet, but it is coming, and it's coming on two fronts. One that we get a lot of noise about, which is risk analysis. What sorts of conditions, diseases, disabilities, might you be especially prone to. One of the interesting things about this, obviously, is that nobody passes this particular test. Everybody has risk factors. We're all mortal. I sometimes have to remind my med students, you know, this is a test that you can't pass. No matter what you do, we will find some risk factor. So, in one sense we have to calm people down a little bit and say, "Hey, you know, we can tell you what you're at risk of and what you're at risk of, but everybody's at risk of something. It doesn't mean you're flawed or somehow deficient."

The other one, besides risk, is trying to match medicines to people's biology. So we know we get a lot of people's side effects, or other people the medicine doesn't work. They take it, they're compliant, but they don't get help with their headaches or their impotence, or whatever it is that troubles them, and clearly there's a biological reason for that. The mapping of the genome, more genetic information, should let us fine tune information about what drugs are going to work, whether it's Coumadin or something else, to the particular patient's biology.

So those are all good things, ethically. What's troubling? Well, for one thing you've got a start to asterisk risk information. And I know, Brian, I know you're an expert of probability and statistics and a wizard of numbers, and patients are not. They get out there and you start telling them you have double the risk of this or three times the risk of that, and they don't understand it.

We've got to get better at how we communicate information to make sure they can get informed choices.

Second big issue – how much spin do we put into it? So I could tell you, well, you're at risk of diabetes, and I look at this genome and it says there's trouble ahead for you if you don't lose some weight, but should I really push harder because they're in a category where they're really at risk of diabetes. Do I yell at them? Do I sort of coerce them? How far do I pressure as the primary care doctor, knowing now that I've got somebody with a high susceptibility of trouble for a particular disorder? Or do I just give them the information and let them change their lifestyle or not as they see fit?

Third big issue – when you do genetic testing, you're finding out things about other people, their children, their biological relatives, and

so, when you find out something...well, let me give you a case. We had a case come up recently. A guy came in for testing, wanted to find out if he had Huntington's disease risk. He didn't, that was the good news. Bad news was, they guy he thought was his father, wasn't. We could pick up non-paternity. Sensitive information comes up like that in genetics and the physician is going to have to be prepared to counsel about it, to explain it.

Dr. Brian McDonough:

So there's really a lot of things we have to think about and as primary care doctors, be aware of.

I'm talking with Dr. Art Caplan. He's the Drs. William F and Virginia Connolly Mitty Professor and Head of the Division of Bioethics at New York University Langone Medical Center. Prior to that, he is well known for his work at the University of Pennsylvania School of Medicine, and prior to that he was in Minnesota, University of Pittsburgh, and started out in Columbia.

And could you envision when you were back at Columbia, the changes we've seen in medicine and the questions that have been answered? I know in my years in television, many times I would turn to you and ask you questions about so many topics, or watch you on Nightline or other programs, addressing these issues. There have been so many things, over these past years, it has to be pretty amazing to have gone through it.

Dr. Arthur Caplan:

You know, I remember, barely, but I do remember, just about the time that ICUs really started to gear up. Today, even a primary care doc is going to spend some amount of time trying to manage all the technology of these specialty units. When I get into the ICU setting in the hospital, I am, I don't say it, but I'm amazed. We have all kinds of technology that can prolong life. We've got machines that can replicate the function of the kidney. We've got machines that can replicate the function of the heart. We've got all kinds of blood pressure meds we're throwing around. We've got powerful antibiotics. It is amazing what can be done. People who would absolutely would have been dead when I first walked through the doors of the Columbia Medical School, they're going on and on and on.

So that's a startling fact about technology and medicine. The other thing that I find surprising is people are just living longer. And so, I remember the population that was there 30 years ago, people used to think about having a geriatric specialty, because if you will, there were relatively few people who were older. Today, the average internist or family medicine person sees a lot of old people because there's just a lot of old people.

I'm not sure they can be a specialty of geriatrics in the sense in which, in primary care you've got to deal with a population that's aging and we're keeping them alive, medicine has helped them, so that's an amazing fact, too.

Dr. Brian McDonough:

So you do all of these things, you see all of these things, what would you say over the past years has been the toughest ethical dilemma that you saw or faced?

Dr. Arthur Caplan:

Toughest ethical dilemma for me, I know what it is. It's dealing with what to do with premature babies. We used to say a baby who was born at 28-29 weeks was premature. Now today, we're down to 23-24 weeks. We know we can keep some of those kids alive. We know that many of them are going to have severe disabilities. We also know that when they're born, many of them are unexpected in terms of the prematurity, but parents are flabbergasted, they're despondent. They're very much disarmed in terms of being able to make decisions. And we've got to make some very hard choices with the parents turning to us to do the right thing, and as it sometimes happens, then the neonatologist and neonatal nurses will turn to me and say, "What do you think we ought to do with this kid, with this disability, and this kind of vulnerability and prematurity?" Those are just miserably hard questions because, I think, we all morally pull for that kid to live and we want to make sure that we try hard to give them that opportunity and at the same time, you're thinking, "Boy, if this child goes home with four other kids, and has a really severe disability, and I know the numbers on divorce and what that can do to a household, where are they going to be?"

I think those are the hardest ones for me.

Dr. Brian McDonough:

If you're just tuning in. you're listening to Primary Care Today on ReachMD. Again, I'm with Dr. Art Caplan and we're talking about ethics, ethical issues in medicine, and one of the things that s come up recently, and I know I see it in my role as a Chief Medical Information Officer, I'm getting more involved on the IT side, and realizing we can communicate with patients, and one of the things that is coming out, and for those of you who don't know, who are practicing, if you haven't gone to Meaningful You Stage II, is the patient portal. It's an opportunity for patients to get records, to get data, to get information.

There's an argument going on right now, should patients be given unfiltered labs, unfiltered reports, unfiltered data, that they can do with

as they wish, or should the physicians be holding on to it as they traditionally have, calling them with positive results or explaining it?

Where do you fall on that? Because I've heard some people say, "we absolutely just give it to the patients." I've heard other people say, "I don't know. You're dealing with some difficult diagnoses. You better make sure they're prepared for it."

Dr. Arthur Caplan:

It's funny you ask that, Brian, because I just did my HIPAA training, annual training today and the law says patients can get their medical records, patients can get a copy of medical information. However, it doesn't really say whether it is edited or interpreted.

I fall on the side of interpretation and help for the patient. I think throwing raw data at them, throwing sort of coarse information at them, it's not empowering them and it's not helping them, and it can frighten or scare them.

I believe that doctors have the professional skills to help interpret that information. I'm not against patients seeing their records. I'm not against people being able to take that information to others and get second opinions. But I think throwing raw data at people, uncooked, just doesn't do them any good. I worry about that a lot. So I come down pretty hard on the...they need help when they're looking at all the different physiological measurements or genetic measurements, or different types of things we can now give to them. They have to have it interpreted.

Dr. Brian McDonough:

Now those who say the opposite, in many cases seem to be getting their way, they're looking at costs, they're look at...where do you see it shaking out from your perspective? Obviously you're at NYU, but you kind of have your finger on the pulse, sort to speak, of a lot of these things. What do you see happening, ultimately?

Dr. Arthur Caplan:

I think I'm losing. I think what's happening is people are saying I want to have access to the raw information, what are you hiding? What are you covering up? Are you making mistakes that you don't want me to see? Are you casting dispersions against me? Impugning me as a patient? I want to see this. I want to see this.

So, what we see happening, I'm afraid, is more and more just throw the gates open and dump the information right out there. I still believe it's a mistake. I still believe it's like looking at raw information about anything. If you're trying to understand your automobile and you didn't have a mechanic to interpret some of it, I think you'd be in trouble. If you looked at a contract and you didn't have a lawyer to advise you, if you looked at numbers and you didn't have an accountant to help you...I think people need some counseling and some assistance with complex information, but I think I'm losing that one.

Dr. Brian McDonough:

You know, it's funny, you talk about the fact that patients will say, "What are you saying about me," I was talking to a patient about that. I said, really I just want to get home. The last thing I want to do is be typing in some bad things about you. Not that you're not important to me, but why? What purpose is there to do that?

Dr. Arthur Caplan:

And even if I thought it, why would I ever write it down anyway?

Dr. Brian McDonough:

Right. And it's funny as you think about the time that's going on in medicine, I'm naive enough to remember the days when you really wrote a note in the hospital not to get paid for documentation excellence, not to be giving the patient...it was more to find out and to tell the next doctor what you did that day so they could catch on and use that information for whether the nurse said they had a bowel movement or not the night before. It was just information being...but now, it has literally become a legal document where you're watching every word.

Dr. Arthur Caplan:

And I think there's too much fear of the law in medical practice. I sometimes have to say to folks, look I know that you're worried that if you don't do every test imaginable, someone's going to come and file a suit, and there's truth in that. I'm not saying it isn't so, but that isn't the way to practice. That isn't the way to do the best medicine. The best medicine is to let some judgment and some interpretation and some professional expertise come in. I worry that we're getting too much of a law driven medicine rather than a patient-oriented medicine.

Dr. Brian McDonough:

You see so much of that. In fact, when you're talking about documents and records, one of the things that I point to is, for instance, an x-ray. I can x-ray somebody...have an x-ray done of someone's arm and the reading will be...he's trying to find out if there's a fracture, but he reading will be 'cannot exclude this. Cannot exclude that. Make sure we don't exclude this.' So if somebody gets that, they're going to

go cancer? Where was cancer in here, and without that perspective of 'oh, no. They're covering themselves from a legal perspective,' that also bleeds into the records.

Dr. Arthur Caplan:

Absolutely right. So we...it's funny you should say that. We're doing a study right now of radiologists and how they handle incidental findings and they often refer them back to the primary care person and sort of say, "deal with it. Here it is. I see a ground glass this. I see a weird shape that." That's great and there can be dialogue between the radiologists, or the imagers or the pathologists and the primary care people, but to put that into the hands of the patient, makes no sense because all you're going to do is scare the living daylights out of them, if they're going to see ten things that can't be ruled out on the average x-ray and think, "I'm doomed," and that isn't what the radiologist was trying to say. So, again, without that intermediary in there to help interpret what's going on, I think, just giving information isn't empowering to people.

Dr. Brian McDonough:

Time for about one more question, and the way I actually tracked you down at NYU was sitting home, watching a ballgame, playing around on Twitter and I said, Oh, Art Caplan is on Twitter, and I followed you, and then I reached out to you, and we got in contact. It was a nice thing, and I bump into a lot of people that way, so obviously, both of us are on Twitter. We think it might be a good thing. But what about the ethical side of this? Like for instance, I'm not making medical comments except the obvious, "don't text when you're driving" "Don't smoke cigarettes," the basic stuff, but I try to stay out of the other stuff. Are there dangers in social media as you see it, from an ethical standpoint?

Dr. Arthur Caplan:

I see them. I see doctors Facebook Friending their patients. I've seen people using email to send out personal health information. That's all trouble.

I think you got to be treating the social media as, not the forum to really be dealing with your patients. I understand there's room in medicine for telemedicine or remote medicine, but it's encrypted and it's in a formal relationship.

I like being friends with patients. I like being friends with people, my colleagues and peers, but not for the purpose of medicine.

Dr. Brian McDonough:

It's funny, my one time being exposed on Twitter was at a local television program where one of the sportscasters with the Philadelphia Eagles was the case, there was a player who had obviously been concussed and was on the field and I Tweeted, "Get him off the field. It's obvious he had a concussion." And wouldn't you know it, they used that later in a broadcast. "Well, even Dr. McDonough knew that" and it led to a whole spiral of things where I came out and said, "yes, it's true," but the reality was, you've got to be really careful because you have to stand behind what you say and really, are you the person to have said it when you're watching on a the television screen.

Dr. Arthur Caplan:

Right. And you may be a fan,. But they're still going to hear you as a doc, so saying I'm doing a diagnosis from my armchair, may not be the best position you want to be in relative to how others are going to interpret that.

Dr. Brian McDonough:

So for those listening out there, in practice, believe me, don't make mistakes and do that. You have to be really careful and be very careful about photos, all those sorts of things. And Dr. Art Caplan, I want to thank you for joining us, and by the way, it's been great.

Dr. Arthur Caplan:

My pleasure.

Dr. Brian McDonough:

If you've missed part of this discussion, please visit ReachMD.com/primarycareday to download the podcast and learn more on the series.

Again, thanks for listening, and Dr. Caplan, once again. Thanks a lot.