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The Ethical Implications of Preimplantation Genetic Diagnosis

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Guests:
Dr. Ann Gronowski is a professor in the Department of Pathology and Immunology at Washington University School of Medicine. Dr. Arthur Caplan is head of the Division of Bioethics at New York University Langone Medical Center.

Bob Barrett: This is the podcast from *Clinical Chemistry*. I am Bob Barrett. The development of in vitro fertilization in the 1970s has revolutionized the treatment of infertility. The ability to culture embryos has allowed for the development of the preimplantation genetic diagnosis. This involves removing a cell from the developing embryos for genetic testing before choosing one to implant. Just like prenatal diagnosis, it is used to screen for various genetic diseases before birth. For women of advanced maternal age or couples with known genetic mutations, the ability to screen of embryos free of certain genetic mutations is reassuring.

However, as with many medical interventions associated with human reproduction, preimplantation genetic diagnosis raises certain ethical questions. The January 2014 issue of *Clinical Chemistr*y published a Question & Answer piece entitled, “The Ethical Implications of Preimplantation Genetic Diagnosis.” The paper summarized the opinions of an ethicist, and attorney, and the director of a preimplantation genetic laboratory.

Today we have with us the lead author, Dr. Ann Gronowski, who is a professor in the Department of Pathology and Immunology at Washington University School of Medicine; and a bioethicist, Dr. Arthur Caplan, head of the Division of Bioethics at New York University Langone Medical Center in New York City. Dr. Gronowski, we’ll start with you, why do you think that ethics of preimplantation genetics is so important?

Dr. Ann Gronowski: Well, the ability to perform preimplantation genetics has great power. It allows us to eliminate embryos that have unwanted traits and select for embryos that have what we consider as desirable traits, right? So with this great power, comes great responsibility. So as the molecular biology techniques continue to advance, we continue to expand the number of traits that we can screen for. And so, it begs the question of what is acceptable to screen for, so are there lines that should be drawn? In other words, are there traits for which we should not allow screening? And I think that we need to ask these questions before we develop screening methods.

Bob Barrett: Are there examples of preimplantation genetic testing that have raised ethical questions?

Dr. Ann Gronowski: Yes. For instance, preimplantation genetics has been used to select for preferred sex, and in some cases that's to avoid a disease that's carried by a particular sex. But other times, it's done for so-called family planning or gender balance; in other words, selecting a gender because of preference. Now, in other cases, embryos have been tested so that the resulting child would be compatible to serve as a stem cell donor for a sick sibling. And in other controversial cases, there's been actually selection of affected embryos so that the child has the same minor disability, such as deafness or dwarfism, as the parents. Some preimplantation genetics laboratories agreed to do this type of testing and some do not.

Bob Barrett: Well what are some of the concerns about preimplantation genetic testing for the future?

Dr. Ann Gronowski: Well, as we discover the genetic basis for various phenotypic traits and as genetic testing becomes easier and cheaper and faster, some people are concerned that it will be easier to screen for non-medical based traits. So these include traits such as height or intelligence or beauty or sexual orientation. All of these traits are influenced by our individual social values. And some worry that this is a slippery slope, really, to tread on. Some of the concern is centered on the fact that there's not enough effective oversight of the development and use of such testing. So, again, I think it's useful to have these kinds of discussions before testing for these kinds of traits become feasible.

Bob Barrett: Thanks doctor. Now let's turn to bioethicist Dr. Arthur Caplan. Doctor, as an ethicist, do you believe that preimplantation genetic diagnosis should be limited to persons who are infertile or those who are fertile but may transmit grave genetic disorders to their children? Or do you consider that it can be used more broadly?

Dr. Arthur Caplan: I would limit it now. Primarily because the ability to be accurate in the testing is not quite to the point where we could say, if I wanted to pick a child with certain traits, whatever those might be, I can actually, if you will, guarantee that that child is going to posses those traits. We're not quite there yet. And morally, it seems to me, in a situation where we're trying to constrain medical resources, using PGD for purposes other than disease avoidance, or trying to identify conditions that might be treatable if you act quickly at birth, it’s hard to justify doing more than that right now.

Bob Barrett: Is it okay to want to create better babies, or does that come too close to eugenics?

Dr. Arthur Caplan: Well, it certainly is eugenics when one says, “I want to build a better baby.” And I think for some properties and traits, it might make sense to say, “If we give this child a little bit more memory or a little bit more musical ability, maybe even a little more general intelligence, that might be a good thing. Enhancing capacities and abilities would be good.” But if you're pursuing those goals and there are risks, meaning if the parents are disappointed because something else still goes wrong and they get a child who is not what they dreamed of, are they going to reject the child? Are they going to make life miserable for the child?

And remember too, in trying to pursue better babies, the definition of “better” is very much in the eye of the beholder. What one group would say is important to them, maybe intellectual performance, another group might be more concerned about physical performance. And I'm not sure we can actually draw a hard and fast line to say, “We all agree that that trait is better.”

So while we try to understand, if you will, what constitutes disease, are we going to try and do something about albinism, which is a disorder in many parts of the world that people despise and hate and think as a curse; but in the U.S. and other countries it is not even really treated as a problem; you just wear your sunscreen and a hat. It seems to me we’ve got enough difficulty right now figuring out what’s a disorder and a disease. We’re not yet ready to go down the road of trying to figure out what's better and best.

Bob Barrett: In general, what types of genes do you feel should be tested for?

Dr. Arthur Caplan: At present, I don’t think we should be testing unless we’ve got very high degrees of accuracy, very low rates of false positives for diseases that are clearly disabling or cause death. In other words, right now, I think we should be conservative with PGD. If you're looking at someone who’s likely to inherit hemophilia, if someone is going to have, say, Cooley’s anemia, if someone is going to inherit Huntington's disease; there are major categories where broad consensus exists, and these are either likely to cause death or going to be very, very disabling and incapacitating.

There are some borderline issues around deafness, blindness, and other conditions where I think there is dispute and we might even give some leeway there, even though there isn't consensus that being born deaf is worthy of trying to avoid it; and honor parents which don't want that to happen, it is not that disabling. But I think that's where we should be at present. Going further right now without much more accurate testing, much better counseling, and much more societal debate about what's better and best, I think is premature.

Bob Barrett: Well, who do you think should pay the cost of doing PGD?

Dr. Arthur Caplan: If you're in a situation where you're trying to avoid clear-cut diseases and disorders that everyone would agree are just terribly burdensome on the person, then I think the public programs, government insurance, or private insurance should cover those things. When you move into the more eugenic-type goal saying, "I want to enhance, improve, make a better baby," I don't think government funds should be there. That should be something that, when it happens, people should have to pay out of pocket.

I don't think that society can move toward trying to use public money to improve children, improve the make-up of the human species until it really is able to say, "We've done everything we can to eliminate disease and disorder." We're not close to that yet, so moving over to the pursuit of improvement when so many people around the world still have to struggle with desperate life-threatening conditions and terribly disabling problems, I don't think that's the right moral priority.

Bob Barrett: And I understand that some parents want to choose embryos that have a defect so that their children can be like them. From an ethical standpoint, do you think this should be allowed?

Dr. Arthur Caplan: I have encountered situations where someone has said, "You know, I want to use PGD, but I'd like to use it so that a person inherits --" let's say, small stature. "We're small and we want a child just like us." Or someone else might say, "We're deaf due to hereditary condition, pick out an embryo that will also be deaf because we'd like to have children like us."

My point of view on this is medicine shouldn't contribute to the creation of children knowing that they're going to lack function or lack impairment that might be viewed as normal. So I would oppose the use of PGD. I understand parents might want that; I understand they might have wishes to form a continuity or a bond between themselves and their children, but I don't think medical skills should be used to make anyone worse off. I think that's a misuse of the testing. It's not a path I would see those who can do PGD pursuing.

That said, I certainly do know of instances where doctors have done that and honored the wishes of a couple to say "Make a child like us." I don't think it is right, but it does happen.

Bob Barrett: And finally, Dr. Gronowski, back to you. Based on your interviews with experts in the field, what have you learned about preimplantation genetics?

Dr. Ann Gronowski: Well, interestingly, despite the varied background of the three experts that we interviewed, their opinions have a lot in common. They all feel that thoughtful ethical decision-making is necessary. One thing to keep in mind with this is that preimplantation genetic diagnosis is an expensive and a really time-consuming process for parents to undertake. Therefore, this is not something that's going to become commonplace for every couple. However, with that said, moving forward, I do think that we need to create forums to debate these issues and to set some boundaries.

Bob Barrett: Dr. Ann Gronowski is a professor in the Department of Pathology and Immunology at Washington University School of Medicine. Dr. Arthur Caplan is head of the Division of Bioethics at New York University Langone Medical Center in New York City. They've both been our guests in this podcast. Their Question & Answer article, "The Ethical Implications of Preimplantation Genetic Diagnosis" appears in the January 2014 issue of *Clinical Chemistry*. I am Bob Barrett, thanks for listening!