

Precision Genetics with Dr. Farhat Moazam

Camille Castelyn and Farhat Moazam

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Camille Castelyn 0:04

Hello and welcome to Voices in Bioethics Podcast. I'm Camille Castelyn and today it is my great pleasure to welcome Dr. Farhat Moazam. She's a Professor and founding Chairperson of the Centre of Biomedical Ethics and Culture (CBEC) of the Sindh Institute of Urology and Transplantation in Karachi, Pakistan. She is an American board-certified pediatric surgeon with an MA in Bioethics and a doctorate from the Department of Religious Studies, University of Virginia, USA. Dr. Moazam is also Fellow of the Institute of Practical Ethics and Visiting Professor, Centre for Humanism in Medicine, UVA, and International Fellow of The Hastings Center, Garrison, New York.

Dr. Moazam, you're doing important work on a global scale. Thanks so much for taking the time to meet with us.

Dr. Farhat Moazam 0:54

Oh, it's a pleasure for me to be here. Thank you for inviting me to do the podcast with you.

Camille Castelyn 1:00

So Dr. Moazam, you recently published a book chapter on genomics and precision medicine, and it was published in 2022. The book's name is *Can Precision Medicine Be Personal? Can Personalized Medicine Be Precise?* So we hear a lot about precision medicine, and that it holds great promise and it's always the narrative that it will change the way that healthcare is perceived and how people live in the world today. But in your article, you say that two thirds of the 7.7 billion human inhabitants live in developing countries. And we have to ask how will these developments take shape in these contexts, which actually seem to be the majority? For example, some people would say that low to middle income countries have bigger health problems to focus on, rather than developing precision medicine, which may only become available to an elite few. So, what would you say to that?

Dr. Farhat Moazam 2:05

Okay, thank you for the question. It's an interesting question. The chapter that you've referred to that is just come out in the book, was based actually, on a conference, an international conference and workshop. The chapter

reflects what the views I had presented over there about precision medicine. And essentially, I had phrased the title as genomics and precision medicine through a different prism. And so essentially, what I presented was, I'm a clinician who's interested in bioethical issues, but I'm a clinician who is practice both in the United States, as well as in Pakistan. So it's really through the gaze of a clinician in a developing country that I wrote the chapter. So the point that you've raised about the accessibility of precision medicine, I think it's an extremely important thing to consider. Because the point is, in a world with limited resources, do we work? How do we balance therefore rights of the individuals versus our responsibilities to the larger world, to the global community, to our community beyond ourselves? So, in the chapter, for example, I've turned to poetry to try and capture two ways, two worldviews. It's a contrast that I have made by using poetry.

So, the one worldview for example, Henley, who is a British poet, this is a very famous couplet from one of his poems in which he says, "I am master of my fate. I am captain of my soul."

The other world view is that from a poet from the South Asian subcontinent, and his name is Iqbal is a beloved poet in Pakistan. And taking couplet from his poetry. He essentially, this is what he says, he wrote it in Urdu so I'm translating it loosely into English. So, Iqbal says, "the link that binds the individual to society is a mercy. The individual is like a jewel threaded on the cord of community." So, if you look at these two worldviews and mastered of my fate versus that the individual is a jewel, something that is threaded on to the community. So, these are two worlds view.

So I think the question that you asked "Where do we turn to?" I would think that the vast majority of the population of the world essentially would perhaps look towards Iqbal way of life, rather than Henley's.

Camille Castelyn 5:18

Yeah, that's really beautiful. Wow, thank you for sharing that with us. I think we hear some of that resonating in the whose uses of language as well, as you describe in the article when they talk about precision medicine and how it connects to the sustainable development goals, and where they use the words and they said that no one must be left behind in the pursuit of healthy lives and wellbeing for all ages.

So we definitely can say that precision medicine has the potential to maybe enlarge, but also close the gap if used in an accessible and just way.

Dr. Farhat Moazam 5:59

Yeah, precision medicine is an arm that grows out of human genomics. The Human Genomic Project, which was completed in 2003, for example, has given us a great deal of very good knowledge. Genetic research, for example, is now underway globally. And it has provided as it has a lot of good things that it has offered to medicine. And it does that essentially by making more precise, both our tests, for example, if you take breast cancer, and also certain drugs that can be more effective, targeted drugs for breast cancer. So this is not to deny that are increasing information and knowledge about human genomics has not been a very, very, major good progress. But I think my criticism of this is exactly in what direction and for what are we going to use this particular science that we have?

So to give you an example, going back on to who will this benefit for your listeners, precision medicine, just a very briefly, basically, what it means is that it is an individualized molecular approach to finding, to diagnose the disease, but also finding a particular targeted medicine for it. So if you look at it, for this, you we will need

extensive biological information, we will need to have that. And that comes through genetic research. So as I said, the research and science it is invaluable. I mean, it is something that has to continue. But in what direction will it go is my primary concern?

So as you've said, the United Nations the Sustainable Development Goals, for example, and you've already quoted that, so the UN Global STDs when they were put together, this was signed on by 193 member states, which includes the United States, and they agreed to the ethical values and what the aims should be that should be achieved by 2030. And in this, the words were that the language was that we must look for global solidarity. We must leave no one behind. We must ensure healthy lives and wellbeing for all, at all ages. And it also talks of tackling the basic things, which is maternal and infant mortality rates. Now, if the world wants to do this, all of this also needs resources. So the decision is where are we going to use those resources? If it will help Dr. Castelyn? Can I say just again, for listeners who may not be familiar with...

Camille Castelyn 9:28

Yes. Please.

Dr. Farhat Moazam 9:29

So, in order for us to move to precision medicine, where each person, if I get a particular disease, I can go and get a medicine that is specific to my genetic makeup, in order to reach that point, there are two things that will be needed for us to do. So for precision medicine to become a reality for everybody, we will need, one is big data. And big data essentially means that we must have large biobanks of genetic material, genetic profiles, genetic tissue, biological specimens, as well as your health data, from patients as well as from volunteers. So that's the one thing we will need: big data.

The second thing that we will need is a term called pharmacogenetics. All it means is that we would need to do research and studies to match exactly which particular drug will work for which particular genetic person. So in this, this will require a lot of clinical trials in which the pharmaceutical industry will play the central role. So if you keep these two things in mind, what we need to move to this direction, which is precision medicine, we will need big data and pharmacogenetics. Two things.

Now, the problem and the issue, and I'm not the only one who has pointed that out, is how will we get big data? And number two, where will we do the research in order to study specific drugs and medicines? The issue is, therefore, both these things require research. And people, as I said, I'm not the only one that's concerned about it a great deal in other countries, including the United States, is that if you're going to do research, which means you need to get specimens, blood specimens, and you need to get tissue specimens, and you need to get data on patients, which is the most likely place where this kind of research will be done? And there's no question about it, that this will be this kind of research will be outsourced to low income and low middle income countries. And the reason is, that's what is already happening. So there is collaborative research, where the money for the research would come from a more affluent country, or some of the organizations, CDC, NIH and others. But the research, etc., would be done in a lower middle class income countries. And the reason for that is we have large pools of people, we have people who are relatively illiterate, they don't know about the rights, it's just easier to collect this data from those people. The other problem is in our part of the world, we don't have very good oversight of ethical research. So we don't have sufficient number of ethics research committees, and those that we do often they

don't work very well. So a major issue, therefore, is going to be in order to move in this direction. Where are we going to go get this research the biological specimens, and after that the trials trying out drugs to see how they work.

So this is a major issue. And I know in Pakistan, and in India and other places, a lot of collaborative work has already begun to collect genetic specimens. And so, this becomes a very major concern, because the drug that will be made out of it, or other tests, etc., that will come out of this research, we know are going to be too expensive for populations in our part of the world to have access to. So this is a major area of concern that you have limited resources, who's going to control where this money is going to go to, where researchers concern. So that's a major problem in beginning to develop moving towards precision medicine.

Camille Castelyn 14:40

Yeah, I mean, thank you for mapping out the path for us, quite clearly about what are the next steps and what water still needs to flow into the sea before we can have precision medicine in the world. And as you say, you raise that very important concern of where will the research take place? And of course, it has to take place in adjust way in which all stakeholders are heard and that it's, as you said, collaborative with these countries and not to these countries, which we cannot accept that this time in history, I would almost say.

Dr. Farhat Moazam 15:15

Yeah, that's true. So for example, look at our track record, where ethics is concerned in how we have and are still essentially handling the COVID pandemic. So in this also, a lot of research was done in order to develop our vaccines, a research was done also in our part of the world. And yet, and vaccines were made, and that's been brilliant. I mean, vaccines have never been made this rapidly before, and yet they are extremely important. But look at what has happened once the vaccines have been made, as far as the distribution is concerned. So just last year, in September, Antonio Guterres, he is the UN Secretary General, you may be aware of the speech he gave in September, in which, and I'll just quote that for your listeners, and he was talking about the vaccination for COVID, and he said, "over 90% of Africans are still waiting for the first dose, whereas a majority of the wealthier world has been vaccinated." And he went on to say, "This is an obscenity. We passed the science test, but we are getting an F in ethics." This is, this is where we stand today. And again, it's a question of who controls the resources? Where is the research done? And how much of that benefit really goes back to places that have contributed to research? So, we have a very bad track record, as far as global solidarity is concerned?

Camille Castelyn 17:10

Yeah. No, I think that that is definitely the key point about the accessibility and we are getting an F in ethics, it's brilliantly said. But I think when we have discussions like this, and just changing the narrative, as you say, and using different perspectives, like poetry, and also from the social sciences, so that the standing view is not just that precision medicine is only for an elite few and only for those who will be able to afford it, but that as it develops, we make sure that all the voices are heard, all the stakeholders are heard.

Dr. Farhat Moazam 17:51

Yes, right, I think the important thing is also that the input and the involvement of our part of the world has to come early. Because this is the time where I'll give you another example as a clinician. So as we moving to genomic based medicine, one of the interesting things that has come out is that if you get genetic information about your patients, then this has to be interpreted, because your genetic information is not yours alone. Because you may have a genetic factor that also affects your families. Now, in order therefore, to use the genetic information wisely, you need genetic counselors, because without genetic counselors who can sit down and look at the information, and then figure out, okay, how do we bring the family? And do we bring the family in or not? You need training in that. And in other parts of the world, and even in the United States, genetic counseling and genetic education is not a primary thing that is done in medical schools at all. And in our part of the world, that's even worse. So in addition to that, for example, in societies where there are vulnerable people in which I would include women, how does one then handle confidentiality and privacy in a family centered society?

Camille Castelyn 19:41

Yeah.

Dr. Farhat Moazam 19:42

Right. I would expect you would see something similar too...

So these are things that have to be thought ahead of time, but as usually happens, sign states off at a breakneck speed and in my experience, ethics kind of tends to limp along and ends up being more as a reactionary thing, rather than being on board right at the start.

Camille Castelyn 20:13

Yeah, that is unfortunately, the case, it seems. But yeah, hopefully we can change that as well. And it's absolutely an important point that you raise genetic education worldwide is very important as we move into the future of genomic medicine and precision medicine eventually, as well. And, as you say, how will we communicate this to the individuals but also within the context, of their local context, their family contexts? And we definitely see that as well in South Africa in terms of much more communitarian approach. And we've had a look at that in one of our previous podcasts as well.

Dr. Farhat Moazam 20:56

Can I ask you something out of just curiosity, please, in your language, not English, in your language in South Africa, in the indigenous languages, etc., is there a term for genetics?

Camille Castelyn 21:08

Oh, my goodness. That's a very good question. I'm not sure. I know, a woman who a few years ago, she did research with the sun population as well. And when she went to go speak to them, she realized that she would have to go completely back to basics in terms of how she would communicate it. And so she developed a lot of illustrations and comic books as well. And she has a big thing about science communication as well in this way. So it's definitely it's, it's definitely something to consider. Yeah.

Dr. Farhat Moazam 21:44

I asked the question because we do not really have in Urdu, which is spoken here, we really do not have the word genetics. So when it comes to, even when you doing research, you want to take tissue to study genetics. Can you imagine how difficult it is then to get your informed consent? How are you going to explain that concept? That's that can be quite concerning, then do you really get an informed consent? Or you've just ticked a little box saying informed consent taken.

Camille Castelyn 22:25

Yeah, yeah. That won't do. Yeah. Those are all fantastic points and points where we have to grow and develop creative solutions as well. Is there anything else that you wanted to mention? Dr. Farhat Moazam? Before we conclude...

Dr. Farhat Moazam 22:42

Just one final point, this is more really to throw this out. I've been a physician for many years now. There is a trend, which is essentially that science has helped us a great deal. There's no question about that science and biotechnology. But what I have seen and this is, this is the pluses of as you get older, you have a historical view for things that have gone on before, there is a trend of for clinical medicine to become more and more mechanical. So what is happening is that in our shift towards science, instead of science being a tool that we use, we are reaching a point where science is taking over so that essentially, we are losing the holistic part of clinical care, which is that you engage with the patient, you don't just look at the x-rays, and you just go and just look at the blood test. And so we started with poetry. And I'm going to, with your permission, end with a poem, this is how I see the unfortunate thing that is happening to medicine. And this is by Emerson is a very well known American philosopher and boy it and he says and this applies to medicine, in my opinion, so here's what he says, this is just a piece out of a long poem, he says, "the merchant serves the purse, the eater serves his meat, things are in the saddle and ride mankind.

I think it's something to think about that it's not the purse that is serving the merchant. And it's not the meat that is nourishing the eater, things have been turned around. So it's things that are now in the saddle. And they are riding mankind. I think biotechnology and some of the advances are now in the saddle, riding clinical medicine, which is a shame. I think we need to give this some thought.

Camille Castelyn 25:02

Yeah, thank you. Those are really powerful words and definitely food for thought, for myself and for our listeners. So thank you very much for your time. Dr. Moazam. We wish you all the best in your future endeavors. And thank you very much for your time. It was great having you here.

Dr. Farhat Moazam 25:23

It was it was my pleasure. Thank you very much for giving me this opportunity.

Camille Castelyn 25:25

Thank you.