Jorge Rivera Reflects on His Experiences as a Lawyer, Advocate, and Hospital Systems Ethics Fellow

Jennifer Cohen and Jorge Rivera

Jennifer Cohen 0:04

Welcome to the Voices in Bioethics podcast. I'm Jennifer Cohen. And it's my pleasure today to welcome attorney, immigration advocate, and bioethicist working as a clinical ethics consultant, Jorge Rivera to the podcast. Jorge, wonderful to speak with you. Likewise, Jennifer, thank you for having me. It's a pleasure. I want to speak with you about all your professional accomplishments. But let's start with your personal story. You were born in Puerto Rico and grew up there. Can you tell us a little bit about your parents, your family, and your childhood in Puerto Rico?

Jorge Rivera 0:37

Sure, it was a very normal childhood, I would say very uneventful. I am first generation in everything in my family, my parents didn't go to school other than, you know, high school, but they made their own business and just work normally. And they really instilled in us to go to school, study, have a profession, they were very adamant about that. And for us, it was a no brainer, no brainer. We really just, I really liked school a lot. In a sense, that wasn't a problem. For me, I loved reading books since I was little and we were very studious, in a sense. So I just had a pretty normal childhood. We'd like swimming. So we had a lot of swimming classes. I remember that a lot. And just being with my, my two siblings a lot. We spent a lot of time together. I have an older sister. She's a pediatrician, and I have a younger brother. He's doing his PhD in psychology. And you know, , just a very normal child.

Jennifer Cohen

Wow, really accomplished. You and your family, your brothers and sisters. And so as you say, you went to college and law school in Puerto Rico, and what were the circumstances around your decision to come to New York and Columbia University to study bioethics?

Jorge Rivera

So I was at the college level, I was a pre-med at some point. But I really didn't know what I wanted to study. So I jumped a lot, I did a little bit of accounting, I did chemistry, I did, etc. And I finished doing a Bachelor's in philosophy. Because I thought I wanted to go to the seminary and be a Catholic priest. My family's very Catholic. So that was just a natural progression, in a sense, but just the vocation wasn't there. So, I decided to do my PhD in philosophy first, but my parents were like, no, no, no, you're not doing that you are definitely doing law school. And that's pretty much how I bumped into, into law school. It wasn't planned or anything. And while in law school it was the same thing, I just didn't know what type of law I liked. And I was doing these conferences on death and dying, and having the meaning of death. And from the legal standpoint, of course, and I just got very curious about that. And I started looking for information in PR there's this group of bioethicists in the medical school that were

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doing some work, and I just connected with them. And my curiosity, you know, grew until I basically found a bioethics program at Columbia, among others. And I decided I wanted to pursue that career after law school, or at least some sort of education in bioethics. And I finally decided for Columbia for very normal reasons. My friends were there. And I thought it was a good place to just transition to, it was a big step because nobody in my family has ever been to the States or lived in the States for that matter. So it was a big change for us.

Jennifer Cohen

Ok, well I want to get back to your work as a bioethicist, but let's move now to your work as an advocate for immigrant's rights. You've done a lot of work in the field of immigration, what first led you to become involved in that work?

Jorge Rivera

So from definitely, I stumbled into immigration work here in New York, that wasn't really a topic of conversation in PR. Yes, we have our share of immigrant communities, especially from like the Dominican Republic, Haiti, etc. But I wasn't that exposed to that conversation. It wasn't until here that I was very much identified with that community and sometimes confused as being part of that community from other people, which is totally fine from my perspective, really. But that's how I came about starting to work for them. I started with very simple things like helping them get health insurance, some court things that they would need help, wills,I stuff like that. And then it as the last administration, with the Trump administration, started their work with immigration from that perspective, they were doing, I became more active with them. And then I started visiting some of the detention centers or places we have here in New York at that time that were housing some kids that were separated from their parents. I was working first as an interpreter for the attorneys because they didn't have a lot of Spanish English speaking people that would help. So it was first mostly helping translate the conversations that the attorneys had with the kids.

Jennifer Cohen 5:07

As most of the media focuses on detention centers at the border, but as you said, there are detention centers in many other places, including New York City, what's it like to visit one of the detention centers? Are most of them in prisons? Or are they in separate facilities?

Jorge Rivera 5:23

Right. So it's different, depending on the contract and all that, right. Sometimes they're not even called detention centers. But once they separate the children, they can be in different places throughout the States in New York, which is somewhat more of a humane part of doing this, they are placed with certain families. So they live in a family home during the night, but during the day, they are in a place or a center. And they stay there throughout most of the day, they do some activities, although from the conversations with the kids they weren't really happy nor were they interesting, they would try to give them some sort of classes. So they would simulate school a little bit, you know, they would try to differentiate them by age, but they weren't very clear about how to do that. And then at night, they will go back to whatever house they were staying at. And that's how it operated in the ones I went in New York. But again, it's very different. The ones that are most more known are the ones in Texas, for

example, where they're actually in cages. And it's very, very different from what I saw here in New York, but I did have some colleagues that from New York went there. And they would talk about just the horrors they witnessed over there. It's very unfortunate.

Jennifer Cohen 6:44

Where were most of the detainees from that you were interpreting for and helping?

Jorge Rivera 6:49

They were mostly from Central America. And I think the youngest I spoke to was maybe seven or eight, I saw even younger, and the oldest was maybe 16, or 17. And I saw over 50 kids per day, more or less, you know, very unfortunate, very sad. And just when you understand well, academically, when you hear about the trauma they're experiencing and how it's going to affect them forever. And then you get to actually see it in the flesh. How they're trying to cope. But it's just not enough. It's very sad.

Jennifer Cohen 7:32

What were some of the things that the children spoke to you about? What were some of their worries and fears?

Jorge Rivera 7:39

They just wanted to see their parents back. You know, they just wanted to see them, they wanted to be back with them. That was all they would talk to. And they just didn't know where they were, they didn't like it. They sure some of them were like, you know, you're treating us okay, but we're here all day, we can't do anything we can't go out, we just need to be around these more kids that we don't know. And, you know, I just want to see my parents, that's all and you know, most of them would ask me, when am I going to see them? Which I obviously don't know, which was heartbreaking to tell, you know, and they all cried. You know, it was just too hard on all of us doing the interviews and the kids, which are half, you know, experiencing a trauma that it's gonna be with them forever.

Jennifer Cohen 8:24

What was your experience working with the ICE officials like?

Jorge Rivera 8:28

So again, here in New York, I only work with the ones in New York, and you could see they were conflicted. And that's how I would describe it. They're very courteous and what not. And then you could see they were somewhat conflicted. But at the end, they were just doing all this.

Jennifer Cohen 8:47

And you talked about the interviews are these what's known as, quote, “credible fear interviews”?

Jorge Rivera 8:53

No, these are different. These interviews we did with the children was part of a larger report we were doing about the experience of immigration with a grant we had thanks to the American Psychological Association. And we were trying to expose, in a sense, what was happening in the centers. And those interviews were part of that. On the critical fears. On the other hand, I worked with the New York immigration coalition a little bit. And it was basically preparing people who were once you come in, you either get detained or you can go into the community and wait for your day at court to see if you have a credible fear. That's why they're called credible fear hearings, and see if you can stay because there is actually something is happening in your home country. And what we were doing with the New York coalition, which they do a lot of things. One was preparing them for that hearing, what they needed to say what are the types of questions you know, hearing their story as well to make sure that everything is in accordance with whatever they need to say. And that was something I was also doing at the time.

Jennifer Cohen 10:04

Fascinating. Thank you for sharing those experiences with us. Okay, let's move to your work now as a clinical ethicist. So you attended, as you said, and you are a graduate of the bioethics master's program at Columbia University. Did you know as a graduate student going through the program that you wanted to concentrate on clinical ethics?

Jorge Rivera 10:26

No I did not. I was always interested in health law. And I knew I was going to be somewhere close to that I really didn't know I was going to be where I'm at today. At first. When I finished the bioethics program, I went into an insurance company, and I was working in the compliance division helping a little bit after I passed the bar, I then went into private practice in a law firm doing Medical Malpractice and Personal Injury. But then I saw this fellowship opportunity. And I just couldn't say no, because I've always wanted to be involved in a hospital system. And I thought this was a good segue to come back into ethics and health care. And that's when I decided to apply for the bioethics fellowship, the clinical ethics fellowship, and lo and behold, here I am.

Jennifer Cohen 11:16

Okay, so as you say, you're currently an ethics fellow at Northwell Health. I think that's New York's largest health care system, with 23 hospitals and 700 outpatient facilities, a school of medicine program at Hofstra Northwell. So how did that come about? You applied for the fellowship?

Jorge Rivera 11:35

Yes. And I went through a series of interviews, and I met with a lot of people. And you know, in a matter of two months, I was accepted to the fellowship program. And I started two months afterwards. As you say, it's the biggest health system in New York. And we are embedded in every hospital, it's around 23 hospitals. So we have the ethics committee, of course, in every hospital, which they need, but we also have the ethics council service, which is also embedded in each hospital. And whenever there's an ethical issue, that the team or the family thinks that they need some recommendation or resolution, we get involved. And that is also part of what I do. And the other aspect is the education as you were saying, there's the medical school, and the ethics divisions get gets very involved with the school doing the ethics portions of the class actually done a couple of classes on informed consent for the medical students and for the residents as well. And that is something we do too.

Jennifer Cohen 12:37

Okay. And how long is the ethics fellowship program to last for you?

Jorge Rivera 12:42

It's a year.

Jennifer Cohen 12:43

A year? Okay. Okay, so let's drill down into this fascinating process at hospitals that I think very few people are aware of. So what are the most frequent ethics consults that you're involved with at the different hospitals?

Jorge Rivera 12:57

I would say definitely, identifying surrogate decision makers is something that we have a lot of problem with or issues. And there's a lot of goals of care conversations, and when usually, the patient doesn't have capacity and we have family members who want certain treatments, and the medical team might want others. So there's an issue that we also try to mediate in many ways. And I would say those are the two biggest issues we encounter.

Jennifer Cohen 13:30

Okay, and I know there are some specific interventions that many times require ethics consults around goals of care and capacity and surrogate one of them being ECMO, the extracorporeal membrane oxygenation machine that is put in place for failing patients to relieve the heart and the lungs many times when they are failing, can you talk a little bit about that process and why that seems to trigger so many ethics consults around it.

Jorge Rivera 14:09

So part of what we try to do as an ethics division is to preventive ethics and a sense of be very proactive of issues that might arise that we know are very common. And as you said, in the ECMO case, there's a lot of commonality in the type that because ECMO is a time limited intervention. This is not something to have somebody for a lot of days or even weeks, we always run into the issue that there's a point of that we have to disconnect, and we need to communicate that to the family. And actually, just as a side note, a lot of the issues that we encounter, it's mostly they surround communication between patients and families and the team. And not to say that they're not true ethical issues out there, but sometimes it's really a problem that wedon't know how to talk to people sometimes, or how to convey a message, and we get called, because there is maybe this very big ethical issue. And all we needed to do was sit with the family or the patient and just talk to them for a little bit. And everything was okay. Or even just educating the medical team, sometimes, we tend to think that doctors are almost living gods. And I'm not saying they're not. But sometimes they all need a little bit of education, just as we all do. But going back to the ECMO, there is a time where we need to disconnect, because it's introducing more harm than benefit to the patient. And it's not providing the intended benefit that ECMO is supposed to give to the patient. And one of the big issues is just communicating that to the family and letting them know that this is a time limited trial, that it's not forever, and that we have tried everything, this is the last resort for us. And maybe we should be talking about shifting the care to something more of a palliative and comfort route. We're not saying we're giving up on them, because Palliative care is an intervention, which is saying we're trying something different, because ECMO is not doing everything that you're supposed to be doing now. So we're just going to try another route, we're not giving up hope, we're giving you a different kind of hope. And that is something that just takes time, and a lot of understanding and a lot of listening, a lot of listening, which is something we don't do as often.

Jennifer Cohen 16:31

It's so much to unpack there. So the communications issues, which you say are at the core of so many of these ethics consults. And I think from what I know, you're absolutely spot on, what aspect of the communications is problematic. I mean, you've touched on it a little bit in your previous answer. But is it the doctor's discomfort at delivering bad news? Is it the assumption that an intervention is the same as a cure or an improvement, and that gives the family hope? Is it the lack of a consistent message from the medical team?

Jorge Rivera 17:10

I would say it's all of them. It's a case by case situation. But I would say it's all of them. As practitioners, we want to cure this patient, right. And when we're not able to do that, it becomes very distressing to communicate that to a family that's very helpful. And that can bring a lot of issues. That's one thing. Sometimes we're very into our work. And we try to explain things. And we are not mindful that not everybody went to med school, and they cannot understand what we're trying to say. And sometimes we just don't listen, sometimes they want the same things that we want. Sometimes the goals are the same. They're just saying them in different ways. And, again, when we listen, we can then align the goals. And I'm not saying it's 100% true all the time. Sometimes the goals are just very different. But I would say like 95% of the times the goals are aligned. And we just need to journey with them and listen to them so we can align those goals. And if they're not, again, listening, so we can address their concerns.

Jennifer Cohen 18:19

And let me circle back to the concept, you raised of preventive ethics, can you flesh that out a bit more? How does that work practically in the clinical setting?

Jorge Rivera 18:28

Atn Northwell, the clinical ethics division, since it's a very robust division, and we get to go through to every hospital, we do rounds with the clinical teams, there are certain services that we work very closely with, for example, palliative, social work, etc. And since we have a really good relationship, they know when to call us in a sense, that's part of the preventive ethics to having a really good relationship with the services so they know when and who to contact. And the other thing is just rounding with them getting to know you, you get to listen to who the patients are. And you get to see if there's been a there's something brewing around sometimes a lot of our consults come from just doing rounds. And we see something that's not maybe, right. And we're like, oh, you know, let me just talk to this patient and see what's happening. Or the teams will call us and be like, well, you know, I have this issue. I'm not sure if this is right, what do you think I should do? And we start a consult. And the other aspect of the preventive ethics, it's just being embedded in certain services, like we were talking earlier about ECMO, just having an automatic ethics consult, when somebody is going to be put on ECMO, for example, that's part of being preventive, because you are already part of the journey, not that family through ECMO, for example, and that's a lot of the ways that we practice preventive ethics.

Jennifer Cohen 19:54

How do ethics consults normally get called?Iis it primarily the staff requesting them?

Jorge Rivera 20:01

Yes. So anybody can call an ethics consult, you don't have to be part of the staff. And we've had consults coming from the family, from everywhere. But the majority do come from the nursing staff. Actually, they are the most connected to the patient's issue. So they get to see all of the things firsthand. And most of our consults come from the nursing staff. And we have a dedicated 24/7 phone line. Everybody knows us. So we also individually get calls. And depending on the system, we also get emails, if you want to send a consult order that way. Sometimes there are issues, for example, a nurse will call and they don't want to give out their name or anything. And that's totally fine. Their request of the consult can be confidential, that is something that we protect a lot. And we might start a consult and be attending will ask like who called the consult? And we will say, I'm not at liberty to say, and that's totally fine. Because we need to sometimes preserve those things. And that's understandable.

Jennifer Cohen 21:05

As you've been discussing, ethics consults are usually called when a very serious problem has arisen when a patient is at a desperately critical stage. Many times these are around end of life issues, termination of treatment due to futility, capacity issues over amputations. It's a weighty responsibility for the ethics consultant, it would seem to me how do you manage the stress of the role?

Jorge Rivera 21:34

Yes, it can be sometimes very stressful, particularly when you get very involved with the patient, you get to listen that much, you actually get very involved with them. And at least my way of coping is, well, we have this big division, so I got a good amount of people I can speak to first, but also just with my family, I just get to decompress when I'm not at work. And sometimes it works out sometimes it doesn't. But you know, time heals all wounds as well. So that's a way of working them out too. But mostly with my colleagues, I get to hash out whatever the stress I'm feeling or they are feeling and it usually helps most of the time.

Jennifer Cohen 22:18

And where do you stand on the debate over certification and board exams for clinical ethics consultants, sort of standardize core competencies in the field as you would with other aspects of medicine? Do you see that as a good thing? Do you think that's definitely coming to the field?

Jorge Rivera 22:39

In a sense it's already there. You just need to maybe push it a little more, but it's definitely there. I like regulation in general. I like that. I do think there is a certain level of expertise clinical ethicists need. And that is something that I welcome. I do worry about the types of information that we actually need and how feasible we can examine the fact of if you have the competency to be a clinical ethicist, but like everything is a trial and error thing. And this is only beginning in our field. And I think, as you know, decades, as we will get something in a better shape and more robust, but I definitely welcome it.

Jennifer Cohen 23:25

Okay, my last question, Jorge, what does your future hold? Where do you see yourself making the biggest impact as an attorney, as an immigration advocate, as a bioethicist?

Jorge Rivera 23:37

So definitely, I really like to stay at Northwell, I'm having a great time here. But also, I really want to stay in ethics. And my ideal job I always joke about is being part of the legal team in the hospital system, but also working part time ethics and having a good balance between the two. In terms of immigration, there's a lot of work to be done. And at least from my perspective, there's a lot of work to be done in healthcare. And I hope I can find that place where I can advocate and make that happen for them, because a lot of them are still without healthcare access. And there is nothing there helping them now besides community based services. But I think that we need to get more serious about the compensation and provide something more robust and more integrated. Because at the end of the day, it's good for them. It's good for us, it's good for everyone. It's just the humane thing to do. And I hope I can work that too. Aside from this in my career.

Jennifer Cohen 24:38

Jorge, thank you for sharing your fascinating work assisting patients and the most vulnerable in our society, and for your compassion and expertise in doing such a wonderful job. Thank you for being on the podcast and best of luck to you.

Jorge Rivera 24:53

Thank you, Jennifer. It was wonderful. Thank you so much.

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