

Episode 2

UNC Chapel Hill Latino Transplant Clinic, Part 1

José and Xiomara Flores share their living donor transplant journey.

The Census Bureau estimates that there are over 60 million Hispanics and Latinos living in the United States, and the Latinx population is the fastest growing minority. As many as 40 million are speaking Spanish as their first language. Although Hispanics and Latinos are more likely to experience kidney failure compared to other Americans, they are less likely to access kidney transplant as a solution, the resulting disparity means more years on dialysis, reduced quality of life, reduced life expectancy, and increased healthcare expenses.

Part of the problem is the waitlist for a transplant, there simply aren't enough organs to go around. If a living donor can be found, then that is a gamechanger. But here we find another disparity – because the process of live donor kidney transplantation can often elude our minority populations.

To address some of these issues, in 2018 Dr. Pablo Serrano established the Latino Transplant Clinic at the University of North Carolina Division of Abdominal Transplantation, in Chapel Hill, with the aim of providing culturally competent and culturally sensitive care.

In this episode we'll hear from José a patient, and Xiomara, his wife and donor, as they describe the challenges they experienced in their quest for a kidney transplant, and the joy they have felt since then. We'll also hear from transplant social worker Daniela Matz, who assisted them.

August is National Minority Donor Awareness Month (NMDAM).

Founded in 1996 by the National Minority Organ Tissue Transplant Education Program (MOTTEP) to bring heightened awareness to donation and transplantation in multicultural communities.

For more information and shareable resources please visit:

<https://www.donatelife.net/nmdam/>

All views and opinions expressed in this podcast reflect those of the participants.

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Resources relevant to Episodes 2 & 3 of Kidney Transplant Conversations

Welcome to Infórmate

El objetivo de ésta página bilingüe es educar a los hispanos / latinos acerca de la donación de riñón en vida.

The goal of this bilingual page is to educate Hispanics / Latinos about living kidney donation.

<http://informate.org/>

National Kidney Foundation:

La información más importante sobre la enfermedad renal.



Provides lots of great information about kidney disease from prevention to transplant, including living donation.

<https://www.kidney.org/espanol>

American Kidney Fund

Nuestra misión es ayudar a las personas a combatir la enfermedad de los riñones y vivir una vida más sana.

Information plus financial assistance opportunities.

<https://www.kidneyfund.org/en-espanol/>

National Foundation for Transplants

Cómo eliminar las barreras financieras para los donantes vivos.

Removing financial barriers to transplantation.

<https://transplants.org/resources/>

Children's Organ Transplant Association:

Recaudación de fondos y apoyo para niños y adultos jóvenes con poliquistosis renal.

Fundraising and support for children and young adults with polycystic kidney disease.

www.cota.org

Episode 2 Full Transcript

Host: Welcome to Episode 2 of Kidney Transplant Conversations. Our podcast dedicated to the kidney transplant journey and exploring quality care delivery, inclusion, diversity, equity and access. I'm Rolf Taylor, your host and series producer.

All views and opinions expressed in this podcast reflect those of the participants.

August is National Minority Donor Awareness Month. Founded in 1996, by the National Minority Organ Tissue Transplant Education Program to bring heightened awareness to donation and transplantation in multicultural communities, focusing primarily on African American, Hispanic, Asian, Pacific Islander and Native American communities. We'll provide a link with more information in the episode description. Please, spread the word, if you can.

The census bureau estimates that there are over 60 million Latinos living in the United States, which is over 18% of the overall population and as many as 40 million are speaking Spanish as their first language. Although Hispanics and Latinos are more likely to experience kidney failure, compared to other Americans, they are less likely to access kidney transplant as a solution. The resulting disparity means more years on dialysis, reduced quality of life, and reduced life expectancy, not to mention the added expense. Part of the problem is the wait list for a transplant. There simply aren't enough organs to go around, but if a living donor can be found that is a game changer. But here we find another disparity because the process of live donor kidney transplantation can often elude our minority populations disproportionately, particularly, Hispanic, Latino, Black and Asian people with kidney disease.

Why do we have these disparities?

Well, as Risa described in our first episode, living donation is complex. It takes a lot of time and many appointments and both patient and donor need plenty of support and the finances and logistics have to work out. But if you are from a different race or ethnicity than your provider, which is likely, because of the underrepresentation of minorities in the healthcare workforce, then, this will add to the complexity of the situation because you may not share the first language as your provider, and there are potentially cultural differences, too.

Aware of the need to address these issues, in 2018, Dr. Pablo Serrano established the Latino Kidney Clinic at the University of North Carolina, Division of Abdominal Transplantation in Chapel Hill with the aim of providing culturally competent and culturally sensitive care. The approach has been a great success. Over the next two episodes, we'll visit the clinic and hear from Jose a patient, Xiomara, his wife and donor. We'll speak with transplant social worker, Daniela Matz and clinic founder, Dr. Pablo Serrano.

Jose and Xiomara Flores came to the United States from Panama in 1999 and established new careers and built a family, but in 2016, a lab test revealed, Jose had some kidney disease and the need for dialysis, and for several years, Jose was receiving dialysis and he was waitlisted for a transplant with a couple of centers. So, to tell us more about their story, welcome Jose and his wife Xiomara.

Jose: Hello.

Xiomara: Hello, thank you, to you for your invitation.

Host: So, for our listeners, could you tell us just a little bit about yourselves?

Xiomara: Well, we are living over here in North Carolina from about 22 years. I got my own business. I love to work in the field of education. My own day-care, being at home and take care of my family at the same time I take care of my business. The most wonderful thing that happened to me, so far. I still learning English because my native language is Spanish, but I tried my best.

Host: Lovely to have you with us today. Thank you for joining us. Jose.

Jose: I'm 56 years old. I met Xiomara in Panama while I was stationed in Panama during my military service. We got married and we moved to North Carolina. We've been living here in Fayetteville for over 22 years, Fayetteville, North Carolina and I've been working as a warehouse supply supervisor. We have two siblings, our son, Jose, is 28 years old and our daughter, Genesis, which was unexpected, that's why we call her Genesis, as a new beginning. She's 15 years old. Pretty much, I've always been an active person. I love the outdoors. Xiomara and I have been married for over 30 years.

Host: Wow, congratulations, that's wonderful.

Jose: Thank you.

Xiomara: Thank you.

Host: So, a few years ago, you found out from a test that you had some kidney disease. Was that a complete surprise or had there been some telltale signs?

Jose: Rolf, I'll tell you, absolutely, it was a total surprise. I was in shock. I went for a routine, normal lab work. I'm a diabetic and my primary care provider asked me to do some labs. In the evening, I had a phone call from the clinic in which I was going to, told me that I needed to go in immediately, that I needed dialysis. And that was the first time I've ever heard the word dialysis. I said, "No, I don't go to dialysis and I don't do any dialysis."

They went ahead and they redid another test. They said my kidneys were not functioning. They were not doing what they were supposed to do and my creatinine levels were spiked high. I would have to stay overnight to see if they could do some treatment to, I guess wakeup my organ so it can kickstart somehow. The next thing I know I was under surgery to put a port in my chest that is going to go straight to my heart and start doing the dialysis immediately, otherwise, they said I would only probably last like maybe a week or so without being dialyzed. So, yeah, it was a total shock for me and it surprised the doctors, too, because they told me I could have dropped dead anytime.

Host: So, the doctors kind of felt like you should have been feeling unwell?

Jose: Right, I was really, still not accepting the fact I had something wrong with my kidneys or something was wrong. It was very frightening at the beginning. There was so much information that I had to soak in, so much other detailed things that I had to take care of, I was always thinking that I would wakeup the next day and no, this is just a bad dream. I still didn't accept it for a while, until they started really being invasive on me.

Host: So, you went from an active life, family life, busy with work. So, then, you went into dialysis.

Jose: Five and a half years.

Host: How was that going for dialysis for that period of time?

Jose: I always told my kids that I lost five and a half years of spending time with them. Every time we had a family function or vacation, I couldn't go, I couldn't attend because of all the restrictions. I had dialysis three times a week, for four and a half hours, plus some prep time. So, you're talking about six hours a day and they always ask me, when can we do something, and this time when you normally spend a lot of time with your family and kids, while they're growing, doing family things. Family fun, family activities, going on vacation every year and pretty much stopped traveling for five years.

Host: During that time, did you have discussions about transplantation?

Jose: My social worker at the facility I was going to she was trying to help me out but two other hospitals, I started to do their test requirements to get on the list. It took

me about two and a half years to get listed and from there on, they kept telling me, I'm on the list, I'm on the top and it seems like it wasn't happening.

Host: Xiomara, during that time did you think about the possibility that you could donate a kidney?

Xiomara: Day one, I wanted to be the donor. If there any possibilities that I could be a donor, I want to be. They tell me, no, you can't. You have another role. You're going to be a caregiver. You will now be the support person for you husband. They just tell me, no. That was very frustrating for me because I want to just try me, they do test me or something.

Host: So, how did you hear about the Latino Kidney Clinic?

Jose: During dialysis one day, I overheard one of my other dialysis patients, that he was going to go to UNC. Xiomara and I did the research and we found out they had a Latino Kidney Transplant Center.

Host: Can you remember back to that time what struck you as different about the approach of the clinic?

Xiomara: What struck me the most was that when I asked them first, can I be the donor, they said, yes. The second-best thing that got me so was they had the Spanish speaking staff member. Everybody in the Latino Transplant. I said, "Wow, it's much better because it's my first language and I feel more confident in it." Of course, when I'm out there with Jose, I try my best, but some words that I need comprehension very well is going to be my language. I said, "Yes, this is the place," and they said yes to me. I can be tested to be a donor and they speak Spanish. Wonderful.

My surgery doctor, Dr. Serrano speaks Spanish. I said, "What, he's speaking Spanish." Wonderful, when you're concerned about your health, you need to know really what they're talking in black and white, while you're expecting, while you're going through, while everything is being tested, you need to know.

Host: So, you agreed to be tested for compatibility.

Xiomara: Yes.

Host: Tell us about what happened when you got the results back.

Xiomara: Oh, my God, I remember like it was yesterday when they called me in the early December. I don't remember the date was, the 4th or the 7th, but my nurse that called me and they told me it was Amy. She told me, "Ms. Flores, congratulations. You've been tested and you're the perfect match for your husband."

And she said this is something wonderful because we don't have that too much often. I started jumping and screaming. I was so happy, and Jose was close to me, and he told me, "I know that in the beginning you were my perfect match. We always said that." Wonderful. I tell a lot of people; we have to be more sensitive

with this situation. Today, it was my husband but tomorrow it can be a brother, a person that needs you. Somebody needs you over there to be a living a donor.

Host: Were your family and your friends concerned that you were going to go down that path?

Jose: A lot of our friends gave us good, positive advice. Of course, there's always somebody that's going to say, "Hey, what about you? What about yourself? You're going to give an organ that you normally would have two of and you're going to be impaired for the rest of your life." She decided. There was no force that made her choose otherwise but she was her own. It was her own decision that she went ahead and said, "I want to do it. I want to go ahead and help my husband."

From there on, friends and family supported us. They couldn't believe that she was a perfect match and I kept telling everybody, "We've been a perfect match for 30 years." So, I mean there's no difference, now, then, what it was 30 years ago.

Host: So, it's a beautiful story going through that process of all of the testing and the talking and the decision making, medically complicated, logistically complicated. Can you imagine that you could have done that if you hadn't been in a clinic that was really quite focused on being able to speak Spanish with you?

Jose: For her it would be a much bigger battle because I'm fluent in English. She is not as fluent as I am. So, I know sometimes, we would have to be separated at one point or the other and she probably would have been lost with information or the lack of information given or to question the procedure and what needs to be done. So, yes, it was very important. It was very critical that she felt comfortable, she felt at ease speaking Spanish with the nurses, the staff, the doctors and it made me feel comfortable that she was also at ease because, of course, I wasn't going to be with her all the time.

Host: It's striking to me the contrast between what happened when you first suggested that Xiomara could be a donor back several years ago and the answer was no. And then, this time, the answer was yes. The Latino Kidney Clinic believed in you in a way that the other clinic didn't feel so confident. So, they maybe understood you better and were able to make a judgment about being able to go forward with this.

I want to bring in, at this time, Daniella Matts, who is a transplant social worker with the Latino Kidney Clinic and I just want to invite you to comment on that kind of dynamic of in the moment, when you're making those decisions, does it really make a difference for you to be able to get behind that process, when you can know people better because of language and communications.

Daniela: Yes, I think there is a difference, not only, in understanding the language, but, also, understanding the Latino culture. We know as Latinos that we take care of our families and we are going to make it happen. We are going to work to (make it) happen. So, if your mother could not be the caregiver, they came up with a plan. Somebody else was going to be the caregiver, so she could donate the kidney. I think understanding the culture and where the Latino population, how important family, how important faith is, it's very helpful.

Host: Well, you know, I think all of our listeners will have been smiling to hear that story about how you felt when you got your test results back and you were able to proceed, but could you tell us a little bit about the recovery phase? You have surgery, you have recovery. How was it during those weeks after you actually had the transplant?

Xiomara: You mean the next day after my transplant? I woke up and I told the nurse, "When can I see my husband? I want to go to see him." They looked at me like, what are you talking about? You need to rest. I said, "No, I feel okay. I feel good like nothing happened to me." The recovery was great. Everything was smooth like Dr. Serrano told me. So far, until now, I'm okay. Nothing really hurt. Nothing missing because people got the idea that, "Oh, you're going to feel like something is missing in your insides." And, nope.

Jose: I envy her because her recovery phase was such shorter and easier. I mean, but, thank goodness, I mean for her because even though she was a donor, she pretty much got out of the hospital. Nobody likes to be in the hospital anyways. She was out the third day. I was in the hospital recovering, which was my situation was more delicate, I was in there for probably a month.

Being in there a month, I could pretty much tell you, I knew the menu for food every single day I had the menu done every time. So, I knew what was going to happen Monday or Tuesday or Wednesday. They covered all the bases. They went ahead and had everything taken care of. I know I wasn't going home questioning any of the procedure or questioning any of what I needed to do education wise, you know, even though, sometimes, I was a little bit tired I went ahead and I got everything down pat and I felt comfortable leaving. In that part, I felt good leaving, but, at the same time, I was very grateful for all the staff and the members of, not only the Latino Kidney Center, but even the recovery team at the main hospital.

Xiomara: It was wonderful. Jose supposed to be out early. Something happened to him but it was nothing. It was one something that happened. You explain.

Jose: During the recovery phase, after certain lab work that was taken care of, they were monitoring me 24/7, and they found out that somehow or the other, the kidney was rejecting. Not rejecting me or the transplant. The kidney was rejecting some of the medication that was given to it. So, the kidney was working fine but the kidney was not accepting the medication given to him. So, they had to do a biopsy and they went ahead and made a study of what the biopsy had given to them. So, they went ahead and adjusted the medication in which, of course, I had to go ahead and spend maybe a week more or a couple days more for it to go ahead and establish itself and they did.

The funny thing of the story was that even the doctors were surprised that this never happened before. They never found out a kidney rejecting medication. They found out kidney rejecting from the body, but, now, it was just because of the well-monitored and they were taking care of me, they found this out.

Host: So, you made a big contribution to science, as well.

- Jose: I hope so. I believe that I did because, you know, if it wasn't for that, they were surprised. I mean I was like, "Really, you guys never seen this before?"
- Host: So, now, you must feel very, very connected.
- Xiomara: Yes. I want to say something to you Rolf. I am very bad person to take medication. After surgery, I don't take my medication for the surgery. I don't even finish because that made me sick. I know now that he has my kidney, my kidney said maybe, "Hey, this is not part of the plan. For 52 years I got a person that don't take medication." The only condition I have is asthma. I don't have nothing else. No blood pressure, no high pressure, no nothing and maybe my kidney said, "Why they going to give me all this medication." I don't know. I just want to think like that like I'm thinking what my kidney was.
- Host: So, the kidney "moved house", and had to get used to the new environment, new rules.
- Xiomara: Exactly.
- Jose: That's right.
- Xiomara: Exactly.
- Rolf: Xiomara, you mentioned the surgery hasn't made your life more complicated in any way, that you feel just the same as before. Is that right?
- Xiomara: Yes. Nothing really changed in my life but let me correct that. It changed for better. More conscious to be healthier, more conscious to be active with my family because this is the way they have to be. I'm showing my kids and Jose because he's the one, he got energy. He' walking to a week like five times a week he's walking three miles. I am walking with him. He's [24:40 inaudible], he's doing exercise. I had to be on his same level to [24:45 inaudible]. Nothing changed. For better, yes, for bad, nothing.
- Host: So, you've really embraced the idea of self-care?
- Xiomara: Yes. Rolf, let me tell you. I just turned 53 last Friday, July 9th. I feel like I have 32, 30 years old. My energy is nothing compared for a few years ago, when I was just like, "No, well, no. It's not my thing. I'm not going to do nothing. I'm going to just watch some TV." Now, I'm proactive. Every time I can do something with my family, I do. It's now much better. 53, but feel like 30. My kidney is okay, just one kidney. I believe I can live for long, long, long time, if I take care of myself. Just to be conscious what we're eating, what we do, that we're proactive.
- Host: So, the whole experience showed you how life is so precious.
- Xiomara: Yes, yes.
- Jose: Absolutely. It's given me a second opportunity of taking a shot at life. I told her, now I have two birthdays. My original birthday, which is December 25th, Christmas

and January 27th, that's when the transplant was done and I give that my second birthday.

Host: Now, our last guest on the podcast, she calls it her "kidneyversary".

Jose: Kidneyversary that sounds nice.

Host: So, last couple of questions and thank you so much for all that you shared with us today. Jose, what are a couple of things you wish you'd known much sooner, much sooner in this whole journey?

Jose: If I would have known about the UNC Latino Kidney Program earlier, no doubt, I would have went there first when I found out about transplant.

Xiomara: Yes.

Jose: It took five and a half years and it took a lot of work and research and my wife is a donor and she was pretty much doing all the legwork with the research in reference to trying to find something else, even behind my back because, at one point, Rolf, to be honest, I was giving up. Sometimes, I just saw some of my other dialysis patients, they were dying. I said, "What, my next, what's in it for me?" But I think God had a plan and God went ahead and made us and guided us to the things that happen and if it wasn't for all that, you know, I probably would have been in a worse-case scenario, right now.

Host: And yet, you found a way to unlock that door.

Jose: Absolutely. Yes, pretty much my wife went ahead and she knocked on that door and like I said this is a lifechanging event and I'm thankful for her and thankful for God and things worked out, an all the wonderful people at UNC-Chapel Hill.

Xiomara: Yes, wonderful, all the staff. Every nurse on the first floor, even the people, the housekeepers.

Jose: Even them.

Xiomara: Everybody.

Jose: Every single person in there, they were rooting for us.

Xiomara: Yes, yes, yes, every single person there.

Host: It's a wonderful story. Xiomara, I'm going to let you have the last word. Is there anything else you'd like our listeners to know about as we close our talk today?

Xiomara: From the bottom of my heart I wish people to listen to this broadcast, educate themselves. If you have somebody with this condition look up the way they do, even with my limitation in English, I read, I translate every word because I want to see my husband, for many years with me, I want to keep him here with me, and be more healthy. No, thinking to be a living donor is going to hurt your life. No, it's not. If I do, everybody can do.

I always tell people that today is my husband, tomorrow is somebody that you love, a neighbour, a son, a nephew, whatever. Do the best you can, educate yourself. Thank you, again, for this opportunity because me and Jose, we want to spread the word how UNC Latino Transplant Center, they are wonderful. They are wonderful. Everybody, thank you, again, and thank you, Rolf, for giving to me and Jose this opportunity. Today, I've got my husband by my side and I know God put these people in our path. Yes, thank you, again.

Host: Thank you both so much and thank you for making us all cry a little bit today and making us laugh a little bit today. Daniela, it must be wonderful for you to hear this kind of feedback about the clinic.

Daniela: It makes it all worth it and it makes us so happy to make a difference and to be able to help and to know we say, "We help patients help themselves," and it is so good to hear this story and also, know the people. There are people with beautiful stories and it is a pleasure to get to know those stories and to get to know the people and to be able to be part of this.

Xiomara: Thank you so much, again, thank you, people.

Host: Thank you, it has been wonderful.

Xiomara: Yes, I like to speak about this miracle in or life.

Host: We are so grateful to Jose and Xiomara Flores for sharing their inspirational story and thank you, Daniella for joining us, too. Please make sure you catch part 2 of our visit to the UNC Transplant Latino Kidney Clinic in the next episode, when we'll talk more with transplant social worker, Daniela Matz and clinic founder, Dr. Pablo Serrano. Thank you to our listeners for joining us today. If you enjoyed the podcast, please consider sharing it with others and subscribing on any of the leading podcast platforms and smart speakers.

We also thank the participants and advisors who helped create this podcast and our underwriter, Veloxis Pharmaceuticals. Join us again soon for more kidney transplant conversations. Until next time, take care and be well.

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