

How the UNC Chapel Hill Latino Transplant Clinic is increasing access through culturally competent care.

Featuring Transplant Social Worker Daniela Matz and clinic founder Dr. Pablo Serrano.

In our last episode we met José and Xiomara Flores and heard about their five-year journey from kidney disease diagnosis to their live donor transplant, which took place at the University of North Carolina Transplant Latino Transplant Clinic. The clinic is the culmination of a very intentional vision, a strategic decision to integrate a Latino-focused Transplant Clinic within the Abdominal Transplant Division at UNC Chapel Hill. Since being established in 2018, they have gone on to demonstrate how workforce diversity and cultural competency go hand in hand in the delivery of quality care.

In today's episode, transplant social worker Daniela Matz and clinic founder Dr. Pablo Serrano look back on Jose and Xiomara's story, share with us insights into how the clinic works, and how they have been able to reduce renal transplant disparities.

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 3 Full Transcript

Host: Welcome to Episode 3 of Kidney Transplant Conversations. Our regular podcast, dedicated to the kidney transplant journey, 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.

In our last episode, we met with Jose and Xiomara Flores, and heard about their five-year journey from kidney disease diagnosis to their live donor transplant, which took place at the University of North Carolina – Transplant Latino Kidney Clinic during the pandemic in late 2020. For our guests today, this story is the culmination of a very intentional vision, a strategic decision to integrate a Latino focused kidney clinic with the abdominal transplant division at UNC Chapel Hill. Since being established in 2018, they've gone on to demonstrate how workforce diversity and cultural competency go hand-in-hand in the delivery of quality care. We're delighted that the clinic's transplant social worker, Daniela Matts and clinic founder, Dr. Pablo Serrano could join us today for part two, to look back on Jose and Xiomara's story, share with us insights into how the clinic works, and how they've been able to reduce transplant disparities.

So, now, we're going to visit with two leaders from the University of North Carolina Transplant Latino Kidney Clinic, Daniela Matz and Dr. Pablo Serrano. Daniela is a transplant social worker and in addition to discussing her experiences at the clinic, she's going to talk about her role as Chair of Multicultural Issues at the Society of Transplant Social Workers. Dr. Pablo Serrano is Assistant Professor of Transplant Surgery at UNC. He founded the Latino Kidney Clinic with a vision to ensure culturally sensitive care provision and to address the disparity of relatively low numbers of Latinx patients accessing kidney transplants.

So, first of all, thank you so much for bringing your patients, Jose and Xiomara Flores to the podcast for the first part of our discussion about the Latino Kidney Clinic. Daniela, you mentioned during our conversation with Jose and Xiomara that it's not just about language and translation. It's really about the Latino cultural. So, your patients feel safe and secure and comfortable to ask questions, to understand the process, and I think that came over really, clearly with Jose and Xiomara. Sometimes, we forget how important feeling comfortable and secure is to having open and authentic communication that allows a partnership between patients, caregivers and providers. Could you expand on the importance of that aspect, as you see it?

Daniela: That is crucial. Like Xiomara said I think it starts with the language, of course. A lot of times, when other providers don't speak the language, they may cut things a little short and don't explain everything and then, of course, there is the cultural aspect, understanding the culture, understanding where people are coming from, especially, I think, sometimes, with undocumented immigrants looking for transplants. It is very important that they trust us and they're able to work with us.

Host: I think something else that came over was that the caregiver role is really crucial in your overall assessment of preparing for transplanted and, particularly, a living donor transplant. There'd been, previously, an assumption that Xiomara couldn't be a caregiver and a donor and, in fact, culturally, this was not for them a difficult problem to solve. They were able to get extra help from their family. So, it seems like prudent, cautious and risk adverse systems can sometimes penalize certain people. So, patients and donors really need to be aware of this and work with the social work team to put in place whatever resources they can. What happens in the absence of an obvious caregiver, say for an unmarried person, for example?

Daniela: Well, unfortunately or fortunately, because they do need a lot of help, patients do need to have caregivers. It's also a requirement from Medicare and Medicaid. And so, if there's not a family member who can help, we work on asking for support from the community, from friends and people are able to find others that are willing to help.

Host: So, you can, basically, volunteer to be a helper in that situation, a friend or member of the family can volunteer to take on that role.

Daniela: For sure, I always tell patients that people want to help. People like to feel good about themselves and sometimes they just need to know that you need the help. Patients, sometimes with their support, it may not be just taking care of the patient but helping with fundraising or helping with finding a donor. There are many ways that people help and work together.

Host: Could I just ask you, Daniela, you have a special role with the Society of Transplant Social Workers, which is to be Chair of Multicultural Issues. Can you tell us a little bit about what that means?

Daniela: Yes, a little group of social workers, they are from all over the West, work with different hospitals all over the West and some international, as well, in Canada and Puerto Rico. So, this is a group where we promote awareness and education regarding racial and cultural barriers. We have a conference every year to also promote education to all the transplant social workers. It's a fairly new profession. So, we also meet every month. We talk about our challenges. We share ideas and what we are doing. So, we are really focused on promoting awareness and advocating to close the gap in transplant barriers.

Host: It's a wonderful model for taking care of patients and I think there's every opportunity for this model to be adapted and applied in other categories, as well. Dr. Serrano, you came to UNC with a vision to improve access to lifesaving surgery. Can you just give us a little bit of background of what you had in mind when you started the Latino Kidney Clinic?

Dr. Serrano: So, I got the opportunity to come to you and see and one of my goals was to setup a Latino Transplant Clinic. We know that the Latinx population has a higher incidence of kidney disease. There's a higher incidence of obesity. There's a higher incidence of diabetes. Also, because your family members also have these issues, then, you have less donors or less people that are available to donate and to help you throughout this process. So, there's multiple papers showing that there's disparities that the Latinx population, the African American population and different minorities have less access to transplants, and we wanted to find a way to make this as equal as possible and try to reduce those barriers. So, we decided to come up with the Latino Transplant Clinic. We didn't want it to be just a translation of our English clinic. We wanted it to be something that was culturally sensitive and that we could address the differences in our culture and how we behave as Latinx people.

Host: So, when you first established the clinic, what was the kind of rate of kidney transplant in the Latino community in North Carolina?

Dr. Serrano: So, our numbers were having a lot less percentage of Latinx patients getting transplanted from our wait list. They had a longer wait time than the rest of our population. Our numbers have got a lot better. Our referrals have increased over 200%. Our time to our first appointment has been reduced by about 50%. We have almost a 99% show rate to our clinic, and we have increased our number of transplants and living donor transplants, also.

Host: So, what is happening in the clinic that is allowing you to move the needle in this way?

Dr. Serrano: The clinic is a great effort. We have a lot of people working in the clinic. We have an **administrative person** that is bilingual, she picks up the phone in Spanish or addresses the voicemails that we have in Spanish and sets up the appointments for the patients, making sure they understand where they can come, at what time. Depending on the dialysis requirements, we have our **transplant coordinator** who goes and arranges all the process of our patients. We have Maria Mendez that is or financial social worker that is a key part of the clinic, dealing with all the bureaucracy in healthcare and dealing with all the cost of it. We have Daniela that deals with all the social work issues, the caregiving and the follow-up. I see the medical side of the patients. What we found out is that with this clinic, a lot of patients got lost in the process because it was so complex to setup an appointment, through all those things with a translator, and having the patients come have a clear communication with a patient and making sure they understood exactly where they needed to be. This is a big hospital. They have to move around and sometimes just going from one study to another, if you don't know where to call and you cannot call somebody quickly, you might not make it and then, lose that appointment and that would set you back a couple of weeks or maybe a month to get a new echocardiogram or another CT or things like that, and just having somebody that can help you through all that has made everything so much efficient, makes us deal with all those roadblocks and get the patient ready for transplant, and the ones that are ready into the OR, as soon as we can.

Daniela: I'll echo everything Dr. Serrano said. I think, also, one thing that I'm so grateful for, all the people who work in the Latino Clinic, they're so passionate about everything they do. Xiomara has really been wonderful, really following up with patients and so, I think that also makes a huge difference.

Host: Just to be clear, that's not the same Xiomara that we met last week in our episode?

Daniela: No, it's a different one.

Host: I just wanted to be clear for our listeners. I was very struck by a couple of things when we talked with Jose. One of them was that he had actually been waiting for five years. Then, when he came to your clinic, it sounds like a big part of the success was being able to remove the roadblocks. The other thing that was really striking was just how deeply he felt, a sense of loss for those five years.

Dr. Serrano: I think that's part of what we're focusing on. A lot of times, you know, our center is very busy and we have a ton of patients and that happens in all the healthcare, in general, in the United States. When you have, as you say, one of those roadblocks that could be that you only speak one language and you need a translator or you live in a different area or you do not have access to healthcare or different things that we can help with, you sort of get sent to the back of the line or somebody else is going to deal with you, and that's what happened with Jose and Xiomara. They had gone to a couple of places, and just because of that, they had said that she could not be a living donor for him that she had to be the caregiver. People were not thorough at trying to find if they had more family members that could do the job and then Xiomara could be tested. The moment that they came here, one of the focusses of the clinic is that we know that Latino families, Latinx families tend to have a lot of siblings and making sure that, as long as they know that it's safe and you can tell the head of the family that this is a safe process, that living donation success rates are very, very good. The outcomes are better than a cadaveric transplant and you can save all this wait time. They can have more people tested and have a good caregiver and a good donor to be able to help their family members. Also, you are helping the people that are waiting for a kidney because you are taking somebody out of that line and getting people ahead, so that everybody benefits.

Host: Also, it is statistically unusual that you would have the partner of a patient actually be a good match.

Dr. Serrano: Exactly, so that was a beautiful story, also. Obviously, normally, if you're related by blood, obviously, your chances of being compatible are way higher because your chances of having the same blood group are very, very high. If you're not that it becomes more difficult and there's ways that we can find to help you through this process, but the fact that somebody that is not related by blood, a friend or a spouse, in this case, can be compatible, are not that common. So, I think that this scenario was great that we could do the testing and the crossmatch came back as negative and we could see that they were both compatible and were able to be donor and recipient.

Host: It's just a wonderful story and I don't think there was a dry eye in the house when they talk about, "Well, we knew we were a perfect match, anyway. We already knew that."

Dr. Serrano: They are a great match. They have a great relationship. I think that this just made their bond even better. They've done pre-transplant, during the transplant and after

transplant, they've always been smiling. They had a great attitude to it. Even though, Jose, talked about all these frustrating times, you know, in dialysis, I think he was still always hopeful and still looking for options to get transplanted.

Host: Daniela, you are kind of on the frontline when it comes to dealing with what we might call the social determinants of health, as a transplant social worker. It seems like a lot of your success is around your ability to work through complexity but, of course, social determinants bring a great deal of complexity, potentially, to patients. Could you talk a little bit about what are some of the things that you do to overcome social determinants that might have disadvantaged a patient?

Daniela: Yes, unfortunately, the social determinants of health is a systemic issue. So, we're not going to fix that on our interactions but what we can do is it's the social work model, really, to meet the people where they are and focus on their strength. So, if, let's say, there are limited finances, but they can be really resourceful, or we know the resources that are available to them. We work with that. If they are problems with health literacy, we find the streams of caregivers that could be helping them navigate through this. If they need someone to talk to them, in a very simple way, where they can understand the expectations of transplant, we will do that. So, we try go meet people where they are and focus on strengths.

Dr. Serrano: We've seen that people want to come and want to get help, want to get transplanted. We keep getting patients. Every time, we have or schedule full. We're seeing everybody with a nephrologist, with the social workers. They're coming to their appointments. They're coming up for follow-up. So, I think that it shows that this can be done safely, and everybody can benefit from it, the hospital, the patients, the community. So, I think that it's something that can show the success of a well-run clinic.

Host: Yes, I just wonder how many of those transplantations would not have taken place if it hadn't been for you having a dedicated (Latino) clinic.

Dr. Serrano: Yes, for sure. I think that those are the happy moments when you go, and you see the patients we have transplanted and see how grateful they are and that's what makes everything worth it. Knowing that we're doing something to help the community and that the word-of-mouth, people say, "Oh, I came here because this patient that got transplanted here told me that you guys are great and that you were going to help us and that you were going to help me answer all my questions and that it's going to be safe." So, that's what makes you think that you're doing the right thing running the clinic.

Host: Daniela, would you like to add to that?

Daniela: Yes, I would just like to say, the word safety, I think is very important because, especially, when you think about emotional safety. I love the story of this patient that heard about the Latino Clinic, had been on dialysis for five years and she was working for a company that she was able to have time leave and family, but they kept telling her she couldn't leave for appointments. She called her clinic and they passed her to me, and she says, "Well, I want to do this, but I can't leave." I said, "You know, you have an HR. Go talk to them. They have to let you leave." She doesn't speak English,

so, I think that comes the fear, as well, along with being a foreigner. Anyway, she spoke. She went to HR. Of course, they're like, "Yes, of course. You can make medical appointments." She had five years and she was just transplanted this year.

Host: That's wonderful. So, again, what we're hearing is the story of for five years, five years on dialysis, presumably.

Daniela: Yes.

Host: And then, there's a breakthrough. There's a way to unlock the door. It takes intervention. It takes problem solving to do that.

Daniela: It takes them feeling comfortable coming to us.

Host: There have been a lot of studies showing that a lot of people that are Spanish speaking, even though they have access to Medicare, a lot of times, they don't know when they can use it or how they can use it. So, part of what we want to have in the clinic was this approach where we would teach them what they needed to do and, obviously, not everybody's going to be a candidate, but we can help a lot of people that thought they were not candidates find a way to get transplanted. If you are in a place where you're having trouble communicating, getting through the very complex bureaucracy of healthcare can be very, very hard and one of her goals is to help the patients through this.

Host: Because the bureaucracy is really quite a labyrinth, isn't it?

Dr. Serrano: That's why Daniela does a great job of talking to patients before. Maria does a great job explaining all the financial situations and Xiomara [21:02 inaudible] helps the through all this whole process, also, telling them where to go, what can they apply for, what aides they can get or benefits they can use to make this process easier and faster.

Host: Is that a case of actually running classes with groups?

Dr. Serrano: So, we actually run a class. Our setup, normally, is that the coordinator would have sort of a one-on-one with the patient and kind of discusses and they'll get a class in the beginning. That's what we do in our regular clinic. For our Latino Clinic, what we wanted to do was make a big classroom kind of event where everybody could show up with their families and we could explain everything to them. Because of the pandemic that has been a little bit rough, and we haven't been able to set it up as we want to but that's kind of our long-term goal, where we can have the patient with the family members and going through all this process explaining the loopholes and the places where they can ask for support to show them how it is safe. A lot of times, it's very common, as Daniela said in the beginning that people don't want to put their family members at risk and making them understand that their family wants to be with them. Right? That this time that they're loose from being on dialysis as Jose said. You cannot go to parties, you cannot go on vacation, you cannot live those moments with your family, are times when your family would much rather go through a procedure and help you be with them and be healthy and live longer.

Host: So, if you're educating groups and families or you're running a class or workshop style, are you starting from scratch?

Dr. Serrano: You have to always try to start and show them everything from the beginning, teach them from the whole transplant process, the medications, the surgery, how transplant works, donation, healthcare system, what they need to apply for, what they require. They're going to have to have a caregiver and all those things. So, it is, we try to go meet the patient since the beginning, so that nobody gets lost in this process from not having the knowledge to come up with.

Daniela: I tell patients that this is a process of empowerment, as well, giving them all the information that they need and telling them the pros and the cons, and you can make informed decisions about everything. So, what Dr. Serrano said about starting from the beginning and providing the whole education is very important. I think we're doing a great job about that.

Host: So, hopefully, there's going to be a way for you to convene your groups, even though, we're in this, whose been vaccinated, who hasn't been vaccinated? Is it safe to do this process? So, I wish you all the best with that and I guess you could use Zoom, but it isn't the easiest way to meet with people. I'm sure face-to-face is better.

Dr. Serrano: Sure, sure and hopefully, we're able to meet, again, face-to-face. Unfortunately, sometimes, with our Latinx population, it's hard doing telemedicine or doing video visits due to a lot of them don't have access to internet. They won't have a smartphone. So, that also has been something we had to deal with. Most of our clinics, during part of the pandemic, we did transition to telemedicine and having, especially, people that were coming from out of the city, have just like a virtual clinic. Our Latino clinic stayed the same and we still had it in person because of this. It was so hard to find a time when we could actually meet with the patient through a computer. We had to understand our population and know that this is the best way to help them.

Host: What are your goals and hopes in terms of developing the clinic further?

Dr. Serrano: I feel we want to keep growing. We want to be able to keep doing more research and finding what other limiting factors are for people to come and get transplanted. There's still a lot of people that don't know about the clinic, that don't know about the clinic, that don't have access to healthcare that are lost in some part of the process, and we want to be able to help them. I hope that we can work a little bit more with the community and make this process, as Jose and Xiomara put it, it's one day that suddenly your life changes. It's not like a subtle event. One day they tell you where you're going to have to go to dialysis and that's going to take half of your life, and to go through all that fear, go to a new place and put your life in the hands of somebody else and do that through a translator is really, really hard. So, being able to talk to somebody in Spanish and talk about your culture, talk about the food, about your family and feeling at home, I think that it's something key and that's what we want to give to everybody. We want to be able to give that to everybody in North Carolina and whoever wants to visit from outside, access to that and be able to help as many people as we can.

Daniela: We just want to help people and make them feel at home.

Host: Well, you certainly have two wonderful ambassadors in Jose and Xiomara. When I asked her, “You feel okay after having your kidney removed?” She said, “Yes.” She said, “I want to tell you, I feel better. I feel better than before.” It was just so wonderful to see how positive and energized they were by that whole process that you made possible for them.

Dr. Serrano: Yes, it’s great seeing them. Every time that I talk to them, I think it’s a great feeling. They’re very, very thankful. They have been through a lot. Just like every other patient that has to go through end stage renal disease and then, all the confusion that all the changes in your life take you, and then, going through transplant and that uncertainty and having the donation process and they’ve done great through all this, always telling us what they need, how they feel and working together to make the best out of it with their family. We thought that they would be great ambassadors for the clinic and for transplant itself for people that, rightfully are, but can have doubts and can be scared about the process. They can show how when it’s successful, it’s a great way to help somebody else and continue with your life with a great quality of life.

Daniela: I like the way that Xiomara Flores normalized being a donor and saying I’m helping my husband. Anybody can need a kidney one day and how she normalized that by she’s, I’m great. “I helped him and I’m doing great and I’m living a healthier life,” and it was wonderful to hear.

Host: Yes, that whole motivation about living a healthier life and being conscious about self-care, when you have one kidney, now. Well, thank you so much. It’s been a wonderful collaboration and congratulations on your success and, particularly, congratulations in what was a very, very difficult year.

Dr. Serrano: Thank you so much, Rolf. Thank you for getting the word out and for this great interview and for getting the word of Jose and Xiomara out. Hopefully, we can keep helping more people like them and we’re just grateful to be here and happy to be helping.

Danielle: Yes, I really appreciate this, Rolf. We were talking about the social determinants of health and how this is a big, systemic issue and think having places like this podcast, where we can talk about it, we can bring awareness, I think that’ll be important. It’s an important way to advocate for change. So, I really appreciate this.

Host: Many thanks to Daniela Matz and Dr. Pablo Serrano for sharing their insights with us today. We’ve linked to some relevant resources that they recommended and they’re in the podcast description. 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 advisers 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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