

## **Taking kidney transplants to the people in rural Michigan.**

### **With Dr. Silas Norman.**

In this podcast we discuss two potential challenges in managing chronic kidney disease and kidney transplants: the first is care when you live a long distance from specialist care, and the second is potential financial barriers. Our guest in this episode, Dr. Silas Prescod Norman, tells us about some very real ways that his hospital center has worked proactively to address both barriers, and with tangible results.

Silas Prescod Norman, M.D., M.P.H is a nephrologist at the University of Michigan, working in the transplant program since 2002, and he currently serves as the co-Medical Director for kidney and pancreas transplant and Medical Director of the Transplant Multidisciplinary Ambulatory Clinics, which see more than 18,000 patient visits annually. Dr. Norman has made numerous contributions to the transplant program including the development of outreach satellite clinics to allow patients greater access to transplant opportunities, the focus of today's episode.

Dr. Norman also serves with and volunteers for a number of organizations related to kidney transplantation, including the National Kidney Foundation of Michigan, The American Kidney Fund, and MOTTEP, the Minority Organ Tissue Transplant Education Program and more recently became an advisor to this podcast, representing the American Society of Transplantation.

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

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## **Transcript**

Host: Welcome back to 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.

In this podcast, we're going to discuss two potential challenges in managing chronic kidney disease and kidney transplants. The first is care when you live a long distance from specialist care and the second is potential financial barriers. Our guest today, Dr. Silas Prescott Norman, is going to tell us about some very real ways that his hospital center has worked proactively to address both barriers and with tangible results. One thing that has a lot of people worried is the closures of hospitals that has been happening in the last two decades and has been exacerbated by the pandemic. The Cecil B. Shepp Center at the University of North Carolina has been tracking hospital closures and reports that across the US, we've seen around 138 closures in the last ten years. Southern states and Appalachian states have been particular badly hit, but this is a national problem affecting all but a handful of states. Every time a hospital closes, someone must travel further for their care and, of course, this is harder for people with fewer resources.

So, why is this happening? Well, there are a number of factors, one major factor is something called uncompensated care. It's a situation where care is provided by the hospital, but the patient cannot pay and does not have the insurance. In these instances, the hospital has to carry the burden of the cost, unless they can reclaim it from state or federal sources. If those sources are limited, the hospital may become financially not viable. In addition, changes in rural industries mean many rural communities have seen a general decline in prosperity and reducing employment and that has reduced the number of people with good insurance, but these people still need care. Hospital finances may be stretched to breaking point, as well. The pandemic pushed many over the edge. A total of 19 hospitals closed in 2020, alone. Another factor in rural hospital closures is shrinking population in the countryside. Although urban and suburban populations have grown significantly, by about eight percent in the last ten years, rural communities are mostly in decline. Fewer people,

results in less investment and fewer supporting services. Now, think about that for a special field like kidney transplantation. All of this means there's a shifting landscape for people who don't live in our cities. It's never been more important that patients do their best to be their own advocates and figure out ways to make healthcare work despite the difficulties and challenges. Their care teams are doing their best to support them, as we will hear from Dr. Norman, today.

Silas Prescott Norman, MD/MPH is a nephrologist at the University of Michigan, working in the transplant program since 2002, and he currently serves as the co-medical director for kidney and pancreas transplant and medical director of the transplant, multidisciplinary ambulatory clinics, which see more than 18,000 patient visits annually. Dr. Norman has made a number of contributions to the transplant program including the creation of a program to transplant HIV positive individuals and the development of outreach, satellite clinics to allow patients greater access to transplant opportunities and it's this that we'll focus on today. He also serves with and volunteers for a number of organizations related to kidney transplantation including the kidney foundation of Michigan, the American Kidney Fund and MOTTE, the Minority Organ Tissue Transplant Education Program and, more recently, became an advisor to this podcast representing the American Society of Transplantation. Welcome, Dr. Silas Norman.

Silas: Thank you for having me, today. Glad to join you and I appreciate the work you're doing in putting on these podcasts. I think it's very important to help get this information to the public.

Host: So, when we think about the provision of kidney transplantation in Michigan, it's a population of about 10 million people. What are the disparities and healthcare challenges that you're most concerned about?

Silas: So, that's a great question. So, there's a number of them. We're certainly concerned about the differences in access to transplant that we see among racial and ethnic minorities. There's also a strong component in Michigan that has a large, rural population where we clearly see differences in access between the urban and rural populations and, perhaps, underlying a lot of this is we see substantial differences

in access to transplant on the basis of socioeconomic means, particularly, among our folks who are impoverished.

Host: And, after the Flint water crisis, Michigan got some bad press for public health. Do you think that overall, the state is doing well with preventive health and public health?

Silas: Overall, I think they are. I think, certainly, things like the Flint water crisis really exposed how vulnerable some of our patient populations are. At the same time, we've had a great partnership with the Michigan Department of Health and Human Services, which has taken a great interest in chronic kidney disease and its prevention and partnered with a number of our local organizations to help minimize kidney disease.

Host: It seems like the Flint water crisis was almost a rehearsal for the COVID crisis, in the sense that it amplified pre-existing disparities.

Silas: Absolutely, and I think the Flint water crisis, very much like COVID, showed how tenuous the situation is for a number of the people that we serve and how it doesn't take much to really disrupt their situation and that they don't have a lot to fall back on when faced with some of these challenges.

Host: So, I took a look at the map of Michigan, and you can see just how vast and rural much of the state is. You've got major cities like Kalamazoo, Grand Rapids and Flint, right out across the south and then, Detroit and Ann Arbor in the southeast corner and that's as much as a six-hour drive from the remote north of the state. So, the University of Michigan is in Ann Arbor in the southeast but, for many people with kidney disease needing a transplant, they've had to find their way down to Ann Arbor or Detroit in order to start the process of transplantation. Could you share with us how you went about taking clinics out to the people?

Silas: Absolutely. So, as you mentioned, the majority of the transplant centers are concentrated in southeast Michigan but we have this broad population and because of some of the reasons we talked about before, particularly poverty, there's a

number of patients who just simply didn't have access to the necessary transportation to get across to our centers. And so, we thought what made more sense was really to take our services out to the communities. So, what we were able to do with institutional support and with the support of our local partners, was to move some of our transplant operations to the local communities and what we did to begin with was we identified some of our local referring partners and we actually setup our outreach clinics in their offices and that allowed us to, one, continue the partnership with our referring physicians. It also allowed there to be a place that many patients were familiar with in their local community to come to. We found in doing this, we saw incremental patients that we wouldn't have seen previously, that the outreach clinics were well-received by both the patients and the referring physicians and with that encouragement and with the institutional support we were able to build until we had a total of five outreach clinics across the state.

Host: Has that also enabled you to extend your network of referring physicians or referring clinics?

Silas: It has. You know, in the same way as the majority of transplant centers are concentrated in southeast Michigan in and around large urban centers, the same is true for nephrology care, in general. What we find, particularly as we go into northern Michigan is that there's very little nephrology care. In fact, we tend to know the names of the handful of nephrologists that are really trying to manage a huge, geographic area of patients. And so, we were fortunate to already have those individuals, as referring physicians to our center by doing outreach clinics. What we really allowed them to do was to send us patients who were otherwise medically appropriate for transplant but, based on their care and knowledge of these patients that they knew really didn't have the means to get down to our center in Ann Arbor. And so, it certainly has allowed us to grow the number of patients that are available for the referring physicians to consider for transplantation. I think one of the most fascinating things we realized about these outreach clinics, we didn't realize about the hunger and the desire to have these clinics in the communities is that the patients know about these things. One of the things I think has been almost funny is that, as we would plan a new outreach clinic and we would say, we're going to think about going to Midland, before we really made any concrete moves, I would have patients

coming to me saying, “Hey, I heard that you’re going to have a clinic in Midland.” So, it’s out there and the patients know, and they were ready for it. If we wondered if the need was there, they were letting us know the need was there and they were ready.

Host: So, they say, “If you build it, they will come,” but as soon as they knew you had started building it, they were ready. So, let’s talk about the clinics and how that works when you’re taking a multidisciplinary team out there because it’s not just nephrology, right? You’re also taking other specialists. So, who do you take out to the clinics?

Silas: Absolutely. So, with the caveat that COVID has changed things for us a little bit, but in order to evaluate people properly, we need nephrology, we need surgery, we need social work, and, in addition, we would like to have a nutritional evaluation in people, and people need our financial coordinators to make sure their insurance and resources are in place. And so, when we go to our outreach clinics, typically, it’s a nephrologist, a surgeon and a social worker, as the core team and, very often, we also have our financial coordinators coming to clinic, as well.

Host: So, lets talk about finance for a moment because, obviously, finance can be a major barrier to accessing lifesaving transplant surgery. What kinds of help are there if you know where to look? I’m sure your financial coordinators know where to look.

Silas: Absolutely. So, I think there are two or three things for people to know. One, as you alluded to, there’s a lot of assistance for people out there. So, one of the things, we really try to emphasize is that, as much as possible, people’s financial resources or the perception of their resources should not be a reason not to pursue transplantation. We, in general, want to have every person who’s medically appropriate for transplantation have an opportunity to have a transplant evaluation and have that considered for them. There are a number of ways we can assist people. One of the simplest ways our financial coordinators can assist people is to look at their current insurance plans, in light of transplantation, and help them say, you may want to change this plan or this plan because your particular insurance plan might work well for you now, but given what we know, coming up for transplantation,

you're going to be looking at XYZ co-pays, if you stick with this plan, or this plan is going to fail to cover XYZ. So, let's make these changes ahead of time to minimize your out-of-pocket costs and that can be one of the most helpful things.

We help make sure people have the proper secondary insurance, again, with the idea that transplant medications can be very expensive, and so, we want to make sure that people have the necessary coverage in place, so that they don't have large bills. We can help connect people to a number of community resources, places like the American Kidney Fund that helps connect people to resources and helps people afford their insurance premiums, to help facilitate transplantation. And then, importantly, post-transplant, all of the major pharmaceutical companies that we work with, all have programs to help people better afford their medication. And so, really, we want people to really be able to focus on their medical care and really let us help support them in making sure that it's affordable for them.

Host: You mentioned that you're encouraging people to look at their insurance and change their insurance. So, you're encouraging long-term planning. Has that become easier because of the Affordable Care Act, setting up more insurance exchanges and making it easier for people to change their insurance, if they need to?

Silas: I think, definitely, I think, definitely. We certainly have patients who are explicitly on some of the plans that have been made available through the Affordable Care Act. I think, certainly in transplantation, the more we can expand access to quality insurance coverage, it only helps our patients and, really, when you think about the cost of transplantation and the cost of dialysis, it actually is helpful to society, in general, that we're able to move people from dialysis, which is extraordinarily expensive, to transplantation. It's not cheap, but it's substantially less expensive over the long-term.

Host: Then, covering the co-pay costs, you would encourage people to look at things like co-pay insurance, as a supplementary insurance.

Silas: Absolutely. So, supplementary insurance, and then, again, there are a number of programs to look at specific medications that people may need and there are a number of ways to have those covered. There are a number of programs that have means tested or income-based cut-offs or sliding scales for cost to help patients afford their medications, to make sure that every transplant that gets done, we can support and make sure people have the best outcome possible.

Host: What I did notice is that there is a society for transplant financial coordinators. So, I double checked, and I think we're going to have to ask them if they'll come and join the advisory committee for the podcast, and we can maybe get a financial transplant coordinator to come and tell us, you know, first-hand, what they're doing. In terms of your outreach clinics, after you've done the surgery, it's vital that patients look after their grafts and have regular check-ups and maybe find medication, maintain healthy lifestyles. Have the outreach clinics been able to facilitate better post-surgery engagement, as well?

Silas: I think so. I think so. A couple of the things we've been able to do are, we want everybody to keep track of their blood pressure, their blood sugars, if that's appropriate, early on, their urine output and some other things. And so, we have a lot of education of patients to let them know the expectations ahead of time. One of the things that outreach has been good for is one, for our patients who are more than a year out, we have the opportunity to see them in the outreach clinics, and that just facilitates everything because their transportation time, as well as distance is cutdown. It also facilitates their support people being able to join the visit with them and that way we make sure that we're getting more clear, accurate information that the support people really understand what's being asked of them. The other benefit we found by being in the office of a number of our referring physicians is that those physicians can just physically come down and see us while we're there and we can run through patients together to make sure that we have a comprehensive care plan for each patient and that we're all on the same page and working together for the betterment of the patient. So, they've definitely been helpful.

Host: So, then, you have the whole team together including the primary care team or the referring team and you can get into alignment for the care plan.

Silas: Absolutely, absolutely. And I think one of the things that patients like to see is that all of their providers are working well together. And so, I think it's very encouraging for the patients to know, in this case, that two of their physicians are directly speaking to each other about their care plan. And so, I can say to the patient, I spoke to doctor such and such and we agree this is the plan and they can say the same thing. I think that is reassuring to the patient, that they're really getting sort of one comprehensive set of care.

Host: What sort of picture are you getting in terms of the outreach clinics impacting disparities?

Silas: So, that's a terrific question because you can locate outreach clinics anywhere, in theory. So, one of the things we did was looked at the map of Michigan, similarly to what you did and tried to say, of course, where are areas or markets, from a business standpoint, that might be good to move into, but, also, with a very deliberate eye of where are our underserved populations and can we make those, two meet? From our standpoint, we could see that the westside of the state was relatively underserved for transplant and so that was the place to go. As we move north in the state, as we talked about the limited amount of nephrology care that's there, we know that that's an underserved area of the state and, as we get north, as we get west, we're also getting into the rural populations of the state. And so, we were able to not just go where there's market share, in particular, but, really, go where the patients are, where they need us, and so, we, deliberately, tried to co-locate our clinic in areas, specifically, where we thought patients had decreased access to transplant opportunities.

Host: I know that in the course of facilitating a transplant, you get to know your patients pretty well. So, is there are case study or story that comes to mind where someone really, obviously, benefited from the outreach and provision of transplant financial coordinators?

Silas: There's probably multiple, but I'll tell you this one. So, we have a gentleman who lives in northern Michigan, up near the Sioux, so in the upper part of Michigan.

Their drive to our transplant center is about seven hours. So, we have a clinic currently at Midland, which is in the middle of Michigan, and so, it's not a short drive, but, you know, a four-hour drive is meaningful different than a seven-hour drive. And so, being able to evaluate this person in that clinic, allowed us to see somebody that we likely would never have seen, simply because of the distance. In addition, this is a person who had limited transportation, a limited social support network and, again, if we were just making them come all the way down to Ann Arbor, with that network, in the past, we would have said this is probably not doable because realistically, logistically, this is not going to work. You do not have the support in place, the transportation in place to make this work, but because of the outreach clinics, we were able to facilitate that and then, in terms of the financial aspect of it, this was someone of relatively modest means, and so, getting finance involved early on, allowed us to really make sure, again, insurance wise, we were in a good place, that we had thoughtful plans around what we were going to do around support and transportation. That we could think creatively about some of the visits and maybe do things exactly the way we typically do for protocol, but can we come up with a circumstance that's going to work for that patient, and we were able to successfully get this individual transplanted and they're doing well.

One of the things for us, as a large academic medical center, on a school campus like a lot of centers are, our historical model has been, as a tertiary care center, people coming to us, and we just expect that people come to us. I think to the benefit of the patients, I think the big cultural shift that we've had over the last ten years or so is the thought that we should really be bringing services to the patients in the communities where they live, trying to breakdown barriers to access to transplant and making it easy as possible for people to get transplanted. It turns out that putting the patient first, thinking about the patient's interests first and what might be best for the patient experience, you can do that and still have a financially successful center. And so, this is not, necessary to do care and cost. There's a win-win here, which is the transplant center and the hospital wins in delivering this kind of care in patients and we're able to move closer to our mission, which is really to get as many medically appropriate people transplanted, as possible.

Host: What year did you start with the outreach clinics?

Silas: Our outreach clinics are a little more than ten years old, a little before that, actually, so, it must be about 12 years old.

Host: And then, along came COVID. Suddenly, it's much harder for you to travel and to do face-to-face outreach. Can you tell us how you switch to more of a virtual care and how you managed to maintain a volume of transplant, since COVID came along?

Silas: Absolutely. So, like a lot of transplant centers we had roughly, too much downtime where we stopped doing evaluations that were non-urgent, at the early height of the pandemic. But after that, we, and the rest of the hospital system, made a very rapid transition to virtual care including in transplantation. And what that allowed us to do was to continue to do transplant evaluations. So, what we do, now, is our initial evaluations for everybody are done virtually and that allows convenience for the patient. It allows their support people to be often on the video call, as well, and hear the information. We don't cut into people's worktime, nearly as much, and then, having done that virtual evaluation, and we do the medical evaluation virtually, we do the nutrition evaluation virtually and the social work evaluation virtually. And so, with all that done, for the patients who otherwise look like their going to be good candidates, then, we can subsequently, set a time for patients to come to their face-to-face evaluation. That face-to-face evaluation, either happens at Ann Arbor or at one of the established outreach clinics. So, that happens and one of the great things for the patients, I think has been in changing the way we do things, it used to be at the outreach clinic, the patient would be there four or five hours. It used to be when they came to Ann Arbor, it was roughly an eight-hour day because they would see everybody and just the way the day was set up. In doing a lot of the history gathering virtually, at first, in having social work virtual or having nutrition virtually, those are less people they need to see. So, when they come see us in outreach, then, they're really, just seeing a nephrologist and a surgeon. Those are half an hour visits each. So, we turned what was a five to eight-hour day for the patient, into a one-hour day for the patient, which has huge benefits for the patient and for us. The patients are often more receptive to the education and the messages we're giving, as you might imagine, as people approach the end of that seven or eight-hour day, they were kind

of running out of steam a little bit. So, I think it's been a lot more patient-friendly and by breaking it up, it does mean a few more visits, but we can work around people's schedules, and we give them sort of more digestible chunks of education around transplants. So, I think it's worked very well. And, as evidenced by our volumes, we're up more than 10%, year on year, so, at least there's evidence by the volumes, this has worked well.

Host: So, you've been able to keep things moving that had been previously setup, even during this time of the pandemic. In the background, I noticed some policy changes were made for things like reimbursement, which means that having a telehealth visit means that you get the same reimbursement as a face-to-face. Is that going to continue do you think?

Silas: I can't say for sure, but I would have to imagine the answer is yes, but, you know, as you mentioned the current parody between the face-to-face visits and the video visits was really under the COVID authorization related to COVID. It's been reauthorized, at least once, and I anticipate, because it's worked so well, I can't imagine undoing this. It's been such a benefit for the patients, it's been a proven efficiency for the transplant centers and other parts of the hospital. So, I certainly hope the billing parody is continued. I think it's been a huge benefit.

Host: Have you experienced any kind of digital divide issues that have prevented people from getting access to telehealth?

Silas: We have. So, in fact, although we did the majority of our visits as video visits, we do have a handful of visits that still are phone visits, right now, and those are for people who, in fact, don't have access to a smartphone or an iPad or some device where they can do the video visits or, often, more frequently, it's that they don't have access to broadband and that's really a limitation. Certainly, when we've done our visits, even some of the video visits, people are clearly at Panera or some other area to get access to wireless, which is great and creative on their part, but highlights, as we push for this, we really have to be cognizant of the patient groups that we're taking care of. One of the things we started exploring is partnering with our local physicians, those folks that we have in the outreach clinics that we're

working with, work to partner with them to see if we can't provide devices, so that people can do video visits from those offices, as one way to still remove that transportation barrier, still allow people access to virtual visits without adding costs in order to get broadband or upgrade phones, just to do medical care.

Host: So, they can host or facilitate a video visit on the premises and then that saves people having to do it from a public place.

Silas: I think so. And that allows, and, again, these local physicians are very invested in the patients, they're very invested in helping move these patients towards transplant and, as we discovered in the outreach clinics where the physician said, yes, come, what do you need us to do to make this happen, I think this is just one more step in how do we, as really one team of physicians and care providers, work in the interest of the patients to help move forward and increase access to transplant.

Host: It's been really wonderful hearing the story of your outreach clinics, today. Thanks so much for sharing all of that with us and it's clear you've made an impact and I'm sure you're going to continue to make an impact in Michigan and, particularly, reaching out to rural patients.

Silas: Thank you. I have a great team that I work with and with that team that's really focused on patient care, we've been able to make some great headway and I hope that we can continue to serve our community and that I so much appreciate you having me on today and taking the time to just hear about how we've been able to improve or patient care.

Host: Absolutely, and I'm sure it'll be an inspiration to listeners, whether they're patients or whether they're professionals to hear what you've been doing there. Any final words you'd like to leave our listeners with?

Silas: Sure. So, what I would like to say, if you have advanced chronic kidney disease, for almost everybody, transplant is recognized as the best therapy for kidney disease, and we want everybody to have an opportunity to be evaluated for transplant. We want to let people know that they can refer themselves for a transplant evaluation.

So, if your physician or care provider has not referred you, you can refer yourself directly to a transplant center for evaluation. So, we encourage people to do that. Don't let the finance concerns deter you from exploring transplantation. We have a lot of ways we can help people and, you know, finally, I might say that care of transplant is a partnership between you, your local providers and the transplant center. We're here for you. We want to help take care of people and we just encourage people to reach out.

Host: Dr. Silas Norman, thank you so much. It's been fascinating and please join us again on the podcast at some point in the future.

Silas: Absolutely will. Thank you for having me.

Host: And 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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