

A counseling psychology perspective on solid organ transplants with Dr. Camilla Nonterah.

Plus: Florida transplant recipients discuss the ongoing impact of COVID.

Our first guest on this episode is counseling psychologist Dr. Camilla Nonterah, who discusses the importance of understanding and supporting transplant patients from both biological and psychosocial perspectives. She also reflects on the impact COVID is having on the mental health of transplant patients. During this episode we also hear from Barbara, John and Ed from the Florida Organ Transplant Association, who share with us their observations and concerns about the challenges of living alongside COVID as a transplant recipient.

Dr. Nonterah is Assistant Professor of Health Psychology at the University of Richmond in Virginia. A counseling psychologist by training, Dr. Nonterah is an expert in the psychosocial aspects of chronic illness by examining health disparities and health equity, health behaviors, treatment seeking, and mental health associated with end-stage organ disease and solid organ transplantation. She is also a proponent of positive psychology.

Counseling psychology for kidney transplant patients emphasizes strategies for coping, processing past trauma, and better understanding the role of personality, attitude, education, culture and beliefs. Positive psychology seeks to build on an individual's strengths and accomplishments to foster resilience and coping skills.

The Florida Organ Transplant Association's mission is to support the transplant community through forums to provide information and financial support for patients, caregivers and organ donor families, educate the community at large on the importance of organ donation, and fund transplant research.

With podcast producer and host Rolf Taylor.

About Dr. Camilla Nonterah: <https://psychology.richmond.edu/faculty/cnontera/>

About Florida Organ Transplant Organization: <https://www.floridaorgantransplant.org/>

We thank the participants and advisors, and our underwriters, who helped create this podcast.

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TRANSCRIPT

Rolf Taylor: Welcome to Kidney Transplant Conversations, our regular podcast exploring diverse experiences and quality care delivery of kidney transplant. I'm Rolf Taylor, your host and series producer. We thank all the participants and advisors and our underwriter, Veloxis, who all help make this podcast possible.

Our interview guest today is Dr. Camilla Nonterah, Assistant Professor of Health Psychology at the University of Richmond in Virginia. And later in the podcast, we'll also be hearing from Barbara, John and Ed from the Florida Organ Transplant Association who will be sharing with us some of their observations and concerns about living alongside COVID as a transplant recipient. Our views and opinions expressed in this podcast reflect those of the participants.

Dr. Camilla Nonterah is a counseling psychologist by training. She's an expert in the psychological aspects of chronic illness by examining health disparities and health equity, health behaviors, treatment seeking, and mental health associated with end stage organ disease and solid organ transplantation. She completed her clinical psychology residency at Medical University of South Carolina and earned her doctorate from Virginia Commonwealth University. Dr. Nonterah's research focuses primarily on physical and mental health in underserved groups and minority populations and is guided by a multicultural framework. Her specific research address can be summarized in three main areas. In addition to the psychosocial aspects of chronic illness, she's interested in the impact of culture and race on mental and physical health and her research also examines positive health behaviors from a positive psychology perspective.

So welcome, Dr. Camilla Nonterah, to Kidney Transplant Conversations. It's great to have you with us today.

Dr. Nonterah: Well, thank you very much for having me. I'm happy to be here.

Rolf Taylor: You know, you've got a really, interesting bio and you're doing some fascinating research, I really wanted to just start with and kind of defining some terms for our audience that may not be quite familiar. Could you start with just a quick definition of what psychosocial means? Why it's important to health in general and also when we're thinking about kidney transplant?

Dr. Nonterah: So, in general, when we think about health, a lot of us focus on the biological aspect of your health. So, for example, if I have organ failure, my kidneys are not working at their capacity level, but then there are also other aspects of health. So, there are psychological aspects of health. There are social aspects of health, and all of these can contribute to one's health outcomes or can increase one's likelihood of developing an illness. So, for example, if I have a family history of kidney disease, it may increase my likelihood of getting kidney disease, but it does not mean I'm going to get kidney disease. However, if I also have some psychological factors that are impacting me, so, for example, I'm not

Kidney Transplant Conversations. Episode 9 Transcript

coping well with the stressors in my life, I'm not eating the best, I'm drinking a lot, may increase my likelihood of getting kidney disease along with the fact that I have the family history. And then social factors that could contribute could also be the fact that maybe I don't have access to good healthcare. I don't have access to good health information and so I don't go see the doctor. So, by the time I go see the doctor, my kidney disease has progressed severely and maybe I'm at the point where I have kidney failure. So, that's what we're interested in when we talk about psychosocial factors. Given that I'm a psychologist, I'm focused primarily on the psychosocial aspects rather than the biological aspects.

Rolf Taylor: So, that's really, that's the emphasis on the behavioral decision making around health.

Dr. Nonterah: Yes, so things such as coping skills, whether you have past trauma, your personality, your attitudes towards health, your beliefs about engaging in certain health behaviors, social factors such as your education, your culture, all of these can impact your health outcome.

Rolf Taylor: So, for example, would one of the areas that you might research, or you might counsel a patient on would be how to learn coping skills?

Dr. Nonterah: So, my background is counseling psychology and I'm trained as a clinician in addition to conducting research in that area and so, part of what somebody if I were to be practicing, health psychologists typically work in a healthcare setting. And so, if a patient comes in and they're having a difficult time managing their stress, managing the fact that they have kidney disease, for example, a health psychologist could help teach them how to better manage their symptoms, but also how to cope with the fact that they have the disease. End stage organ disease or kidney failure is a - - it can put a lot of burden on an individual. It's not uncommon for people to experience depressive symptoms, anxiety and other psychological symptoms and so, a health psychologist would counsel them and will help teach them different skillsets they can do, different ways in which they can build their psychological health so that they're better able to manage their illness.

Rolf Taylor: I've heard it said quite a few times by people who've received a transplant, not just kidney transplant but different kinds of transplant, that there is a kind of - - there's a slightly strange feeling about having somebody else's organ inside your body and sometimes that takes some processing.

Dr. Nonterah: Yeah, I mean it makes sense. And depending on your background, so again going back to the psychosocial aspect, your culture, your spirituality, your faith, people have different belief systems about what it means to have a foreign body in your body, a foreign organ in your body. And so, if somebody has beliefs that or they have spiritual beliefs that do not align with that, it may take a while for them to understand that this is the best treatment for you.

Kidney Transplant Conversations. Episode 9 Transcript

Rolf Taylor: Do you think that sometimes the counseling psychology part of the picture is overlooked during the management of patients?

Dr. Nonterah: I do think that is accurate, and I'll say it for two reasons. I think, first of all, when somebody has a health condition, especially if it is severe, their main focus may be on: What do I need to do to be healthy? What do I need to do to live? What do I need to do to be able to just exist? And so, as a result of that, they may not think about the fact that this is a difficult experience that I'm encountering. Having this disease may be traumatic for me. They may not be aware of the fact that their experiencing some depressive symptoms. They may not be aware of their anxiety and so sometimes people are just focused on all we think then that you don't see - - they don't see these other aspects, the psychological aspects until after they are in recovery. So, there's some research, when we look at cancer patients, for example, there's some research that suggest that a lot of cancer patients, they're fighting the good fight and doing everything to recover. And then, after they are in remission, then they start to deal with all these psychological symptoms because they haven't been focusing on them. They've been focusing on what they need to do in order to live. And so, I think that's one aspect of things, but I think also, in general, there are a lot of hospitals that are doing a better job with this, but I think we need to understand that health is not just your physiological health. It's also your physiological health and they're connected in many ways and then also your social health, right, and they're connected and so unless we understand these connections, we are not able to see the person in this holistic manner to be able to treat them and so, I think part of it is this gap in knowledge of understanding that all of these factors matter when it comes to taking good care of a patient.

Rolf Taylor: So, you've got all of this consideration about psychosocial medicine, clinical psychology and then you're focusing on transplant. How did you get to that kind of place where you have this intersection, this overlap?

Dr. Nonterah: So, my journey is an interesting one. I will say in general I'm the type of person who has a lot of interest in things and sometimes it's, or especially when I was younger in my career, it was harder for me to narrow my interest because a lot of things were interesting to me. So, like I mentioned before, my background is counseling psychology, and this is the field that focuses on the emotional, social and physical concerns of individuals with a goal of enhancing their wellbeing. And counseling psychologists are also interested in social justice issues. They're interested in the ways in which somebody's social identity, so, for example, their race and ethnicity, their gender, sexual orientation may affect their psychological wellbeing, and they use a lot of strength-based approaches and, also culturally relevant practices that are based on scientific evidence. So, when I say, "culturally relevant practices," it means that as humans, one of the beauties of being humans is that we are similar in many ways, but, also, we have differences and culture definitely impacts the ways in which we go through our world and so we may have a treatment that's effective. But if it's effective for one group of people, it does not necessarily mean that it will be equally effective for the other group of people or maybe it

Kidney Transplant Conversations. Episode 9 Transcript

would be effective. But for it to get it to be most effective, we have to tweak it and make it culturally relevant. So, counseling psychologists are really interested in that. And for me, I was exposed to a lot of different experiences during my training. I trained to work with college students at a counseling center, conduct a group therapy at a community clinic, was in a weight loss program where I was creating interventions for or helping administer interventions for teams. I also conducted psychosocial evaluations for patients who are interested in getting weight loss surgery and also getting an organ transplant and so all of these shaped my interests, and then, I also had these wonderful mentors who were doing work in areas that ended up kind of becoming a significant part of what I do today. So, for example, one of my mentors, Dr. Heather Gardiner at Temple, she specializes in health communication around solid organ transplantation and kidney disease. Dr. Shawn Utsey specializes in the psychology of the African American experiences. And then Dr. Everett Worthington specializes in positive psychology. So, with working with all of these people, I recognized that I was really interested in organ transplant outcomes, but I wanted to focus primarily on looking at health and equities and then also looking at the impact of the mental health aspects of the concerns of people who have end stage organ disease as well as what makes them thrive, what makes them successful, especially when they're on the other side after they've received an organ transplant.

Rolf Taylor: So, you mentioned about being interested in health disparities. And in area such as kidney transplants, what are those areas that you're really most concerned about?

Dr. Nonterah: You know based on the literature and some of the work that I've been doing, we see that there are a lot of disparities in access to transplantation. The majority of my work focuses on kidney transplants, but I have done some other work with other solid organ transplants. With kidney disease, we see that there's several steps to getting a kidney transplant, so one of the steps may be expressing an interest in getting a transplant, being referred to a transplant center and then going through the pretransplant evaluation, which basically says that you qualify to get a transplant because we do know that there are more people in need of a transplant than there are available organs. So, we have to make sure that people are ready to get their transplant and we have to make sure that they're going to be taking their medications very diligently because we don't want the organ to be rejected and so the pretransplant evaluation is a big step where we do see a lot of disparities in access. Then, there are other steps such as being on the wait list and if you have, for example, getting a living donor. These disparities have been documented for over two decades in the literature. We've seen so many things that have been proposed as contributing to these disparities and we've also seen some good work that has been done to look at interventions that are trying to address these disparities. A lot of the interventions have focused on patient education. Also, some interventions have focused on using social workers to help patients through the process. We also know that there's clinicians who are doing some really good work using more culturally relevant or culturally tailored programs to help patients. So, for example, I know you featured Dr. Serrano on the podcast highlighting the work from UNC's Latino Transplant Clinic and

Kidney Transplant Conversations. Episode 9 Transcript

then also Dr. Simpson at Northwestern has an African American Transplant Access Program and the whole idea with these programs is that maybe some culturally relevant practices that are necessary in order to make patients comfortable and to make them get through the process in a way that they're less likely to experience barriers and they're more likely to be seen as being a viable or a good candidate for a transplant. So, all of this work has been done and more recently some researchers have also talked about the importance of looking at things such as structural racism and how this may play a role in terms of access to transplantation.

Rolf Taylor: It seems that with some populations where there is a disparity, where there appears to be less access to transplant, for example, that something that's going hand-in-hand in that with that is kind of lack of trust or less trust in the system. Is that something that can be helped if providers take on a slightly different approach or are thinking more intentionally about building trust with their patients? Is that an extra step that needs to take place?

Dr. Nonterah: Definitely. I think if we look at the history of the U.S., there are a lot of reasons why certain communities may not trust hospital systems. You know a lot of us think of the big examples like the Tuskegee Syphilis Experiment, but there's so many more. That's the one that's talked about over and over again. There are so many examples. And so, as a patient, if, for example, I'm a patient and go to my nephrologist and I'm trying to get a kidney transplant and I don't trust my nephrologist, I don't trust that the hospital system has my best interest, I may come in as appearing to be a little resistant or a provider may label me as noncompliant or difficult, but there's a lot more to it than that and so, I think providers should be very careful about how they're labeling patients and make sure that they're not ignoring their concerns. They're not just saying that "Oh, this patient is noncompliant. This patient is difficult," but trying to understand that the patients have legitimate reasons for feeling cautious about how they navigate the healthcare system based on their personal experience but based on also the experiences of their investors and their family members and so on. And so, as a provider, it may require educating yourself. It may require a little bit more time just to understand why the person may be reluctant to take your advice, why they may not be doing the things you think they need to do and some of it could also be because a person generally has some significant barriers. So, transportation is something that a lot of people take for granted, but a lot of patients experience difficulties with transportation. And if I need to be attending my appointment multiple times and I don't have adequate transportation, I just cannot pursue a kidney transplant and so these are things that providers have to be aware of and have to take a little bit more time to understand their patients.

Rolf Taylor: And that's kind of part of the discussion I think about structural racism where there's something happening, which is in the process, which is in the system, and a little bit of mistrust is perhaps part of that because it sets up a disconnect, so one of the ways that we can perhaps overcome structural racism is trying to remove those communication disconnects that we have.

Kidney Transplant Conversations. Episode 9 Transcript

Dr. Nonterah: Definitely and I think there are a lot of tears when it comes to dealing with structural racism. A big part of it is the fact that we need better laws and regulations that reduce disparities based on one's identity because in reality, we shouldn't have the disparities we have and that's why I prefer to use the term inequities instead of disparities because in reality, there should not be a case where one group of people based on your identity, based on your racial background, based on your gender, based on your age, that should not be a reason why you're more likely to not receive the best treatment or to be diagnosed with a certain illness versus somebody else, but there are these laws that create these inequities that may increase the likelihood of one group of people being more susceptible to an illness and being less likely to get the best treatment to manage that illness.

Rolf Taylor: And sometimes even well-intended laws and policies actually have an inequitable effect.

Dr. Nonterah: Exactly. Exactly, and part of that, too, is so even as a researcher, I have to think about the ways in which I conduct my research. So, for example, we're very good - - a lot of researchers are very good at targeting interventions that fit the middle class and they fit people who, for example, have access to things we take for granted such as the internet, transportation and so on. And so, as a researcher, if I'm conducting my research, I have to think about who is able to access my research. Am I creating a system where regardless of your background, it's easy for you to access my research so that I can learn about you and then also I can create interventions that really are effective for you? Because an intervention that works well for somebody who has a middle-class background is probably not going to work very well for somebody who comes from a lower income background where they don't have access to some of the things that somebody in the middle class may take for granted.

Rolf Taylor: So, even though it's more difficult and it's more complicated to do, we need truly inclusive research so that all participants are represented and we're learning about how different types of people behave in those situations.

Dr. Nonterah: Exactly.

Rolf Taylor: You mention in your bio about positive psychology. Can you talk a little bit about that? I think I know what it means, but I'm not certain. When you talk about positive psychology and how is it helpful to people who are waiting for or have had a kidney transplant?

Dr. Nonterah: So, positive psychology is a field of psychology that's focused on character strengths and behaviors that allow people to thrive. Another way you can think of it, in the media, a lot of people are talking about living your best life, right, so how do you get to live your best life? The reason why this is important is because we know that if you're thriving, you have better health. There's a lot of research showing the relationship between traits such

Kidney Transplant Conversations. Episode 9 Transcript

as optimism and having better health, things such as being resilient and having better health and so positive psychology is really interested in these characters and traits and behaviors and looking to see if we can have a better understanding of how these can influence health outcomes. And if, for example, in a clinical sense, if you have a patient and they're very optimistic, you can encourage them to build on that as they're going through their difficult conditions. So, in this case, they've been diagnosed with end stage organ disease, and they have these wonderful traits, you can encourage them to lean on that. We know that some research suggests that spirituality is helpful for people in managing a health condition, especially a chronic illness, and so we can encourage patients to hang onto that and to really harness these strengths that they have so that they've better able to deal with their illness and that can relate to better health outcomes.

Rolf Taylor: And I think one of the things that's observable in so many transplant recipients is this feeling of gratitude and it's very profound. It often seems to be almost like a spiritual awakening, that gratitude that people express after they've received a new kidney.

Dr. Nonterah: So, I'm conducting some research right now and a lot of the patients expressed this sense of gratitude for having a new lease on life, for being able to receive this gift that allows them to spend more time with their family and so on; and I'm interested in getting together all the data so that I can have the findings presented in a manuscript. A lot of this research has not been done in general in the area of transplantation and most of the research that's been done has been out of the U.S. Some of the research has been done within U.S. and so we need to have a better understanding of this so that we're better able to support patients because we know that for a lot of researchers, we're interested in problems, right, and so we focus a lot on problems, but I think it's also important that we focus on what things are working really well and those can help us to develop better interventions and to be better able to support our patients.

Rolf Taylor: That's really, really fascinating, so I hope you can come back and talk about that research at a future date.

Dr. Nonterah: I would love to.

Rolf Taylor: We recently convened a discussion group with some transplant recipients and especially from the Florida Organ Transplant Association, FOTA, and we had a small group come together and we talked about kind of what is front of mind right now as we enter the third year of the pandemic, dealing with all of the changing mandates around masks and social distancing. We distilled this down into an eight-minute edited discussion about what thoughts were coming to the surface and I thought it was really striking that it was really the psychological challenges that were really coming to the surface. So, for people who'd had a transplant, the COVID pandemic had exacerbated the challenges. When you listen to the group, we had Barbara, John and Ed, it's clear that the isolation from staying home has been really hard.

Kidney Transplant Conversations. Episode 9 Transcript

Barbara: My name is Barbara, and I was transplanted, a heart transplant recipient on September 22nd, 2006, and last year I celebrated 15 years with Robin. She is the woman I got my heart from. Donate Life and Life Alliance in Miami after 10 years told me who she was.

John: My name is John. I started dialysis the day after graduating high school and I was on dialysis probably for about eight years, which I got my first kidney transplant back in 1986, and that kidney lasted over 28 years. After another four years on dialysis, I received a second transplant, which was five years ago.

Ed: My name is Ed. I had a needle stick (injury) back in the '70s and got Hep C (from the injury), transplanted (liver) on Valentine's Day 1998.

Barbara: I don't like to call it a journey. I like to call it a road trip. I got my heart when I was 65. I'm not a youngster. I'm a very lucky woman to have gotten this heart transplant when I did. I've always given back to transplant because they gave me and my family so much.

John: I work for the University of Miami Transplant Program. I was a supervisor of the Transplant Satellite Clinic for over 25 years and now I'm the Executive Director of the Florida Organ Transplant Association. We help patients and donor families. I run a support group online. Just moving ahead hopefully to open a transplant center in the near future.

Barbara: I have to be honest with you, I have been very protective of myself. My family has been extremely overprotective of me, but I have reached a point in my life, and I spoke to my coordinators and my doctors about going out again and spreading the word about transplantation.

John: As Barbara said, I also am out and about at all events and still do what I used to do. I still take all the precautions, try to help a lot of people get the information they need about COVID because a lot of the patients called me wondering what's going on, trying to keep myself safe and trying to help other people to stay safe. I worry about what happens if I ever get it. The only thing we can do is keep going and take precautions as we need. I always carry my hand sanitizer, my mask, gloves when I need them and that's the best we can do.

Ed: COVID has messed with our communication system. We have meetings in Pompano and down in Miami every month and we'd have a yearly meeting or two and now we can do this like we're doing today, but it doesn't have the same pizzazz as we used to have and it's really unfortunate that while nobody wants to communicate with anybody because nobody wants to be around anybody because they're afraid of getting COVID. I wear my mask. I wear my mask in the car. I even wear my mask in a car when I'm there with my son because he's out talking to people.

Kidney Transplant Conversations. Episode 9 Transcript

John: People I know, I have no problem telling they need to wear a mask, especially around me or any of the transplant people that I know, but of course you walk in the stores and people are not wearing masks. And if you try to say something to them politely, they give you either a smart remark or they make gestures at you, so you really can't say anything. I mean this is what they want to do, but they're not realizing that they're hurting other people, too.

Barbara: I just know that everybody has their own opinions. I know I'm for masks. I'm for people wearing them to protect me and their family and everybody out there, but you can't always make people go along with your idea. So many people are on that side that you don't have to wear it and so many people are here that you have to wear it and I've learned that you have to respect everybody's feelings whether it is they take it or they don't, whatever. I think it's all become a lot of politics. You have to address them, I like to say, nicely, but you can't start an argument with them and that is so difficult out there when you're trying to promote this mask-wearing for their benefit, for their family's benefit. It's a strange world we live in and people that are refusing to wear masks and this and that and honestly, I don't know what to do about it. I don't know what we can do about it.

Ed: We can't do what we used to do because we all have to hide. You have to go from your place of work with your mask and go home and hide and you can't, I mean John used to get four or five, 600 people in a room.

John: Yeah, a lot of people I'd like to know if they're protected or not. I mean I received the booster, but I still don't know if I'm protected or not. There's a lot of tests out there on where different opinions. I mean the hospitals are telling us not to get the antibody test because it won't make a difference. There's nothing they can do about it, so there's a lot of discussion about that on the support group too because people like to know. There is a new website, actually a Facebook group by Johns Hopkins that explains a lot of the antibody tests and tells you which one is the correct one to get for transplant patients.

Barbara: I'm talking to so many professionals about it and some agree, and some don't, and I have to say that I, myself, it's a gut feeling, and I have to go along with my gut feeling. That's always helped me through a lot. That we don't have any protection as a transplant recipient as long as we're on these immunosuppressants.

John: Well, listening to the other people on the support groups, you know the major concerns are the antibody levels, but also there are some people that really are afraid, and they just don't know what to do. They don't want to go out. Is the vaccine going to hurt my organ? Am I going to be able to go out again? It's a lot of concern and try to put people at ease. On the support groups, everybody talks to one another, so it helps a little bit.

Barbara: I have decided to get back out and work with the public and spreading the word, so I think about it. And as a transplant recipient, I say, "I have to do yet what I have to do to

Kidney Transplant Conversations. Episode 9 Transcript

spread the word.” You know how many people die every day that haven’t been transplanted and we don’t have people that have registered to be organ donors. I don’t want to get it and I don’t want to give it to my family or anybody, but, yes, I will be wearing all the protection, but I have to get out there and I have to do it before I can’t do it anymore.

Rolf Taylor: Dr. Nonterah, what are your thoughts about dealing with the stress of isolation, which are particularly difficult for someone who’s had a transplant and has to be doubly careful?

Dr. Nonterah: The pandemic has put a lot of burden on a lot of people and for transplant recipients, it plays additional burdens on them, the sense of isolation, but also this fear of how is this virus going to impact me? What are people doing to keep me safe? How do I protect myself? Because there’s a real fear that the organ is going to fail for transplant recipients and so I think, first of all, we have to acknowledge that it’s been a really difficult two years. We’re about two years into the pandemic right now and I think sometimes a lot of us are focused on like let’s move on, let’s move on, but we have to make space to have some grieving done. We have to grieve the loss of social connections, the loss of some loved ones because some people have lost some people, also the loss of your ability to move and do things that bring you joy and so I think it’s important that we acknowledge that and it’s not surprising that people are experiencing some psychological symptoms. I think if most of us are honest with ourselves, during parts of the pandemic, a lot of people were experiencing having maybe a low mood, feeling isolated in different ways, some anxiety and so it brought up a lot of psychological symptoms for people who don’t have the additional burden of having a transplant. So, you can only imagine how that could be exacerbated when you do have a transplant, as well. It’s important to process that experience and process what it’s been like and it’s also important to find ways of being connected and so some of the ways in which people can be connected... So, first of all, you have to acknowledge that it may not be the same, right, so I may not be able to have connections with people in person as a transplant patient because I have to be very careful about going out into the world and so maybe using Zoom, using all the different forms of like video chats, also using phone calls, going on walks, relying on one’s faith, one’s spirituality, if that’s something that’s important to you and I also think that if you can see a psychologist or a social worker, see a therapist, a counselor, somebody who can help you process some of these difficulties and also help you problem solve. So, the nice thing about therapy is it can be a place where you’re free to be who you are. There isn’t that fear of judgment. You’re not worried about overburdening somebody because you’re calling this friend all the time and talking about how down you’re feeling or how intense you’re feeling. It could be a very faith space for people to be able to talk through some of their difficulties, but I also want to acknowledge that not everybody has access to therapy because there are some barriers for people for a number of reasons and so maybe even if you are a spiritual person seeing like your faith-based leader could be something that’s helpful. I encourage you to lean on that if there are ways to have your support groups in, again, more safer spaces, whether it’s meeting by Zoom or phone calls, checking on each other, those are all... Those are some examples of things people could do.

Kidney Transplant Conversations. Episode 9 Transcript

Rolf Taylor: It's the talking that allows the processing and that's something I think that the people are missing because it's like Ed said in the recording. He used to go to these meetings where there'd be like a hundred people at and that's kind of hard to do. That's kind of hard to do on Zoom, so he's really missing that. He's really missing that. Like you said, he's kind of grieving for that thing that was lost from his life, but at the same time the Zoom support groups are helpful. They are allowing people to express how they're feeling, getting it off their chest and acknowledge all the changes that we've been going through.

Dr. Nonterah: You know, again, that's why I say, there is a loss, right, but we're also making the best out of a situation that is not under, a lot of us, our control and so for somebody like Ed, it's important for him to acknowledge that he has lost something that was very valuable to him, and to accept that loss or at least work towards accepting that loss, but also to think about ways in which he can get a little bit of that support that he was getting from before. So, it may not be the exact same thing. It may not look like the exact same thing, but can he get a part of it that was very helpful for him?

Rolf Taylor: And I think something else that comes over from people who've received a transplant is that there is this feeling of being different and that this is heightened by the vulnerabilities that come with being immunocompromised and the greater need for mask-wearing by transplant recipients and people around them. So, how can transplant recipients help make sure that this feeling of differentness is not detrimental to their lives, to their health? And do you think that positive psychology is helpful to this situation?

Dr. Nonterah: Feeling different is something that a lot of people who have an identity that differs from the majority struggle with, right, and so in this case transplant recipients, if they have this specific identity that makes them different from the rest of the greater majority and so it is normal to feel that way and it's normal to have some struggles as a result of feeling different. You know a big part of what makes us human is we all want to belong. We want to feel like we are special. We want to feel like we are seen. I first want to say that there is a continuous process in working through that difference and in getting to a place where you feel comfortable with your difference and that's something that a lot of people have to work through. It doesn't happen overnight and there are times where you feel a lot better. Maybe you feel like, oh yea! I'm proud of being this transplant recipient and having this identity and there are other days where it may feel more difficult because you're not in a setting in which you feel seen. And so, I will say that one of the important things to do is to find your group of people because when you find your group of people, it's easier to feel seen. It's easier to feel supported. You're better able to work through some of the difficulties you may be experiencing about the fact that maybe there's certain things you can't do or there's certain things or they're certain people in your life who maybe are not accepting or understanding of some of the difficulties you have as a transplant recipient. And so having that space with people with shared interests, you get to share stories. You get to hear about some of the ways in which people have dealt with different things. Hopefully, as you work through that, you get to a point where you start

Kidney Transplant Conversations. Episode 9 Transcript

to realize that being different is a wonderful thing. It's not necessarily a bad thing. If we all look the same, if we all had the same experiences, if we all have the same type of life, our world be extremely boring. Our world would not be fruitful and with those differences like strengths. So, thinking about, as a transplant recipient, all the things you've overcome, thinking about all the things you have experienced and the fact that in some sense you're still standing, you're still getting up every day and you're still pursuing life, that is an amazing strength. That is something that a lot of people are not going to experience. That's a unique experience that has a lot of beauty to it. And so, I think as you work through this process, as transplant recipients work through this process of getting more in touch with their difference, they can start to see some of the positive aspects of these differences and lean on those so that when they have these moments where they're feeling isolated or feeling like they don't belong, they can take pride in their identity.

Rolf Taylor: And I think so many people take that strength and that experience and all the things they've learned and then gift that to other people to help them through that journey, which is another really positive aspect.

Dr. Nonterah: So, I work with undergraduate students, and they conduct research in my lab, and I can tell you that so many of them have talked about the fact that in speaking to transplant patients, transplant recipients specifically and having this gift of hearing their stories has changed their lives in many ways. I've heard a number of them say, this has been one of the best experiences that they've had in their lives because they get to hear from, like you said, they're gifting somebody else with this their story and helping somebody so that when they have difficult experiences in their lives, when they have experiences in their lives where they're feeling different, they can hear these stories and they know how to learn from them in order to feel like they can thrive and live their best possible life.

Rolf Taylor: Thank you so much for joining us for this episode. I really enjoyed our discussion. Are there any closing thoughts you have for our listeners that just you'd like to share in terms of staying healthy and staying positive in the long-term and particularly for our listeners who are transplant recipients?

Dr. Nonterah: So, I will say for transplant recipients, get as much support as you can. I think we take for granted the fact that as social beings, we're all connected. And in order for us to thrive, we need each other to thrive and so really use the social support that you have. And if you don't have the social support, try and build that support. There's a lot of evidence that show the value of social support and how that has really helped reduce the burden of certain physical illnesses and mental health illnesses and so use that support. Also, allow yourselves to just be human in the sense that you're going to have some down days. There's some days that you're going to feel like this is a very difficult experience. You're going to feel burdened by your disease and just allow yourself to have those days. It's important that we understand that as part of the human experience, we're not going to be happy all the time. We're not going to feel upbeat all the time. There's a place for every

Kidney Transplant Conversations. Episode 9 Transcript

part of our human experience and so I would like to overall say to transplant recipients to remember that. And then, I think, overall, in general, if all of us to the listeners who are not transplant recipients, if we can recognize the importance of supporting our recipients, of supporting our patients in very little ways and part of it could be learning a little bit more about organ transplantation, learning more about the gift of donation, learning more about what it means to be a donor and then as healthcare professionals, also taking some time to see our patients in this holistic manner and recognize that they're not just a statistic. They're human beings with full lives and so how do we help them thrive?

Rolf Taylor: Something that I've heard said so many times is that when it comes to resilience, it isn't about toughing it out. It isn't about strength and determination, alone all of that's important, it's a lot about the preparedness just to reach out and seek support and talk things out.

Dr. Nonterah: We need each other. Again, like I said, we're social beings and we need each other in order to thrive, so it's important. I understand that sometimes we feel vulnerable when we have to share some of the difficult aspects of our lives with people, but it's important to take a little bit of a risk; and it may be a little risk and then you test the waters to see if this person is a safe person, but it starts with that little risk and sometimes you may be disappointed, but I hope you do not give up. And also, overall, if you do have access to a mental health counselor, a mental service, definitely make use of that because mental health providers are trained to provide that safe space.

Rolf Taylor: Dr. Camilla Nonterah, thanks so much for joining us today.

Dr. Nonterah: Thank you so much for having me.

Rolf Taylor: Thank you for listening to Kidney Transplant Conversations today. We hope you enjoyed the episode and please remember to subscribe and share. And thanks again to Dr. Camilla Nonterah and our friends from the Florida Organ Transplant Association – John, Barbara and Ed – for joining us on the podcast. Kidney Transplant Conversations is underwritten by Veloxis Pharmaceuticals, Inc. All views and opinions expressed in the podcast reflect those of the participants and do not necessarily represent the views and opinions of Veloxis Pharmaceuticals, Inc.

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