Living Transplant Season 4 Ep 8

[00:00:00] Living Transplant is a podcast that takes you behind the scenes of the transplant program at Toronto General Hospital, with the goal to educate, inspire, and fuel your passion about transplant. I'm your host, Candice Coghlan. Thanks for joining us for season four. In this episode, I sat down with Justin Boy, a father, entrepreneur, and businessman who has lived with multiple types of renal replacement therapy since the age of 10, including three kidney transplants, chemodialysis, and more.

and peritoneal dialysis, as well as home dialysis. Justin and I spoke about mental health, resiliency, parenting with a chronic illness, and how to appreciate each day. Later, we were joined by Samantha Anthony, the first person to hold the title of Health Clinician Scientist in Canada, Transplant and Regenerative Medicine Center, Department of Social Work, Child Health Evaluative Science Research Institute at SickKids.

We explored the medical journey and tools to support children, youth, and families created from the perspective of [00:01:00] those who live with it. We also spoke about post traumatic growth and the whole family journey. Please enjoy. Welcome back to the Living Transplant Podcast. It is my absolute joy to have Justin join us today.

Thank you so much for joining me. Thank you. I'm wondering if you can start off by, uh, telling us a little bit about yourself. Well, I'm, um, I'm, I'm 53. Oh, actually I just turned 54. Oh, happy birthday. I was born in Toronto. I, uh, went to university here, graduated in radio, television, broadcasting, and then started my advertising agency.

And I've been running my company for about 30 years now. And, um, uh, I'm married. I have, uh, two older daughters from previous marriage and I have a eight year old son. So you, uh, you mentioned there a little bit about, uh, your health journey. I'm wondering if you can, uh, bring us back to, to your childhood and, and talk to us a little bit about, um, what [00:02:00] growing up was like.

Every year. Especially when you have health challenges, a year can seem like a lifetime. So when you add all 54 of them together, it seems like a very long time. But, um, you know, growing up when I was pre 10 years old, before that, I had a great childhood. I was very active. I was really good in sports. I was an avid skier and avid swimmer.

Um, I even got my instructor spin in skiing when I, by the time I was, uh, 11 and, um, and then I got sick. And so what happened was, um, my back in, what was it? In 1976, my, uh, parents wanted us to take a trip to China and, um, we went back to visit sort of our ancestral village and whatnot, and when we were there, I got a strep infection and my father being a physician, a surgeon at the time, he always carried medications with him, but obviously he couldn't do a swab or he didn't know [00:03:00] what type of antibiotic needed.

So he started sort of a broad spectrum antibiotic. I took it, but then I kept getting sicker. And they got me back to Hong Kong and I got better. But then six months later, I, it was, that was Christmas break. And by March break, I went to the washroom and there was blood in the toilet bowl and, and so that's how quickly it happened.

And I was actually really scared. To tell anybody I hid it from my family for a while because I thought I was dying. So I was 10 years old. I thought I'm buying it. I'm gonna tell my parents. And, um, but then eventually what happened was I was going to the washroom, like, literally every 45 minutes. I had to tell my dad.

He took a sample to his hospital. Um, uh, which was Scarborough General at the time and, uh, and they said I had to go in and I went in to see kids. And at the time, they, you know, they always aggressively tried to save the native kiddies for children. So they put me on, you know, pumped me up with steroids and, you know, I looked like all the kids you see on steroids.

That was very tough. I would say that [00:04:00] that was my introduction. To learning how to cope with not just the health issues, but the self esteem issues and all the rest. I mean, it was, uh, it's very tough as a kid to begin with. And I was, I would have been, uh, 11 at that time and 11, 12. So that's already a tough time.

And, um, and then by the time I was, uh, 13, I was told that I had to go on dialysis. And at that time I chose peritoneal dialysis because, uh, you know, the belief was that peritoneal is a little gentler. You'll be able to grow more. And, um, so I went on perinatal dialysis and back then the waiting list was very short.

I was, uh, on the transplant list and actually within 10 months, I got two calls. Um, the first call came within like four months. And that, um, my mother actually declined because apparently it was from a, a baby and the kidney would have not have been enough to support me right away. So I would have still had to stay on dialysis for a year, so they [00:05:00] said, yeah, better not.

And my mother passed on that one. But then 10 months later on Christmas Eve, I, I got my first, that's a kid's, wow. And um, what a. Yeah. Yeah. What a gift. Yeah, it was, it was pretty amazing. I actually, I, I, I tell people the story all the time. I remember waking up and Santa Claus was at the end of my bed in ICU.

We had all these gifts. So I spent Christmas and New Year's in the hospital. I spent a lot of holidays in the hospital. And then I, I went home, you know, but again, I Back then, the way they managed medication, when you have a transplant, you know, with all your antirejection, that's a, especially the kids, they really pumped us up.

Um, obviously they want to make sure the organ works. And, and so, you know, I, I was on a lot of steroids again, and I'll tell you, by that time, I was, 14, 15, 16. That's when, you know, you want to look good. You want to, and it was rough. That was really, really rough. Um, you know, side effects from medications can actually sometimes be worse than the illness itself.

Um, you know, cause back [00:06:00] then, uh, I know they don't, they don't use a cyclosporine for renal transplants anymore. They use them for liver transplants, but You know, I was on a lot of cycles for and so, I mean, I was 14, I was shaving twice a day and, and, you know, I had these big puffy cheeks and it was, it was, it was bad.

Like, I would say that when I went to clinics. Most of my complaints were actually about the psychosocial issues that were happening in my life and not so much the physical issue. The physical, I could totally handle, but it was more, look at how I look like, you know, how do I, how do I fix all this? You know, I remember I was having a lot of emotional problems when I had my second transplant and I went to the nurses and I said, is there anybody I can just, just talk to?

It's been sick since the early eighties. And they even had trouble with finding somebody who was alive still, you know, and I said, well, all the people I know are dead, so I can't talk to them. I said, I'd like to talk to somebody who's been struggling with this for over 25 years, and they ended up finding a girl.

[00:07:00] I actually, it was funny, she and I ended up, we're in camp, a dialysis camp together back in the 80s. And, uh, and I, and they put me in touch with her and we, you know, we've kept in touch, but it is a, it's a different journey when it goes on for decades and decades and decades. And when you go on, when you lose like two, three transplants, then it gets a, there are a whole bunch of other issues that you face that you didn't have to face the first time around.

I try to keep my mental health. I, I focus as much on my mental health as I do on my physical health, you know, um, was it maybe, it's gotta be 15 years ago, I got cancer and, um, it was just, they had deemed it was from all the years of being on immunosuppressive drugs. That time though, and oh, plus I was on dialysis.

So, like, I remember, I remember after that first appointment at Prince's Marriott, I was like, Great. I'm on dialysis. I've got cancer. And it seemed overwhelming until I just said to myself, you know what, [00:08:00] done all this before I can do it again. And, um, and I just talked right through it. Actually, if it wasn't for all those years previously being on dialysis, I wouldn't have gotten through that.

Um, and, and I just talked that all up to mental health like being in a good place. And, uh, and I don't know, I mean, everybody's got their own constitutional makeup and, and, um, you know, I know the, I've used, certainly I've used the support system. I actually used to lead a peer support group for the kidney foundation.

You know, sometimes as a leader of the peer support group, you actually get just as much as the people in the group. And, um, and so I, I just learned a lot of these skills throughout the years. And I think that everybody's got to try and figure out how. To learn those skills because all sorts of curveballs are going to be thrown at you, right?

Yeah. So when, when you were a teen and you're going through all of these changes, um, you know, how did that [00:09:00] impact your, your daily life? And, you know, you talked about having all of these, these feelings and, um, Um, how did you manage all of that as a teenager? And I guess I'm maybe asking you this for, you know, any of the young people who might be going through something similar, who are looking to you for some thoughts and advice of how you managed it.

So I've, I've said this to many people before that actually I, I don't look at kidney disease or anything that's happened to me health wise as an impediment. Actually, I look at it as an impediment. Honestly, I would not be the person I am today if it wasn't for that. Um, I think that, you know, and by the way, going on PD as a kid didn't help with the growth spurt.

I didn't grow at all. So, you know, being shorter than everybody, uh, being smaller than everybody, looking a little different. If I couldn't compete on the same playing field that every other kid was competing on, then I found something else that I could do that was my own thing. [00:10:00] And that's exactly what I did.

So I've always been artistic. And, uh, when I felt a little socially awkward, well, I just delved into my art and I gained a lot of respect among my peers for the art I created and, and winning awards and things like that. So I think if you just turn your focus to, it can actually help you focus. on another part of your skill set than relying on your looks or, you know, relying on your strengths.

Um, it, it really made me look into me and, and even drove me to the career I do today. I guarantee I wouldn't even have my ad agency. I would have probably done something completely different, you know, like my brothers, I probably would have gone overseas and worked for some corporation. I think that's such great advice from you to rather than looking at everybody else turn inwards and, you know, find what makes you feel like You're lighter and brighter and more yourself.

And, you know, that helps you focus on something other [00:11:00] than, I guess, what you're going through at the time. You know, I mean, my, my biggest message to people run into any type of chronic illness, especially something like dialysis and, and, and transplants where, you know, if you're young enough, you can live with it for a long time, is that the psychological aspect and the emotional aspect is probably bigger than the health.

And so I've always looked at it like this. Um, and I like, I actually really liked the term and I don't know when they created it, but renal replacement therapy, you know, sometimes the transplant, sometimes it's dialysis. So I look at it this way. Sometimes you have a transplant, sometimes that's the light just keeps going.

You don't stop. Um, you know, I, I lost this chance, but I had it for 15 years. Um, this kidney, which was from my mom and, uh, I lost it right at the beginning of COVID. But I didn't skip a beat. Like I just said, okay, well, life will be different now. And I literally, in fact, I do more now than when I have a transplant.

I, I never. [00:12:00] Skip a beat at all. I just kept going and, and I look at, you know, I, I, I'm very fortunate. I'm on the nocturnal chemo program. So I have a machine at home, you know, during the time that I'm setting up, I just look at it like, you know, like as if you have to go to the gym or make dinner to get ready for bed.

And it's just part of my bedtime routine, you know, a little bit longer TV in the room and turn the TV on and watch news. And, um, and you just get set up and in the morning you get up a little earlier and come off the machine. And it's, um, it's really. I think that has been probably the healthiest aspect to be able to look at whatever is happening, just accept that that's the way life is right now.

So you don't have to put on hold anything because that, that time may not come right. And, um, with the, with the transplant waiting list these days, and not everybody can find a donor, a living donor, the wait can be long. I, I, I can't even imagine what it would be like to put your life on hold for five, six, [00:13:00] seven years thinking that all these amazing things are going to happen when you have your transplant.

And, and to be honest, some people, when they get the transplant, they don't even feel that great with the transplant. Like it's, it's a different form. But, you know, even patients where they still feel good. So I agree with you, you know, it's whatever part of our journey we're on. Um, I think some people don't realize that, you know, it's a, it's a lifelong journey.

Transplants not a cure. It's not the end of. our problems. It's not the end all be all. And for some people transplant, you know, doesn't ever work or it's just, it doesn't fit in their life either. For some people, they live their entire lives on dialysis and they're able to manage very well. And you know, that that's how they do it.

I think, you know, the more we talk about it as this lifelong journey that we're on is as kidney patients. And like you said, finding. Ways to have it be part of our life instead of stopping our life because of it. I'm [00:14:00] wondering, you know, you spoke about you have two brothers, you know, you've got children yourself.

How does your, how does your family work into this whole mix? Because, you know, everybody who I, who I know, um, it's, it's less of an individual journey often when we are living with a chronic disease and more of a family journey. Well, the way, the way I look at it, and I've always looked at it as a kid, that this is my problem.

So I don't want my problem to affect anyone else around me negatively. My mom, even when I was a kid, has always offered me, but I had a lot of calculations in my head, even as a kid, and I was a pretty mature kid. I thought, I got two brothers, they need my mom, uh, so I refused it every time she offered. And it wasn't until After my second transplant fell, that was on Dallas for those seven years, I decided, okay, maybe it's time to consider another one.

And my mother just happened. I never asked her to come. You go for your physical, your [00:15:00] appointment with the, the, the transplants or doctors. And, um, I was actually going to bring my ex wife and, um, and then my mom said, no, no, no, no, don't bring your ex wife. You should bring me. So I thought, okay, fine. I'll bring my mom.

I'm like, at the time I was like 40, but anyway, so I'm with me and in the, in the. Um, and it never dawned on me to take a living person's organ, like it never dawned on me that someone should even have to experience a minute amount of pain for me. We were sitting there and, uh, my nephrologist said, Turned to my mother and said, Oh, has anybody in the family ever?

I was like, Oh, don't bring this. Like, you know, my mom was like, Oh, is it still a thing? I'm not young anymore. And my mom was in her sixties at the time. He said, Oh yeah, no, we totally could. So then we went down to the lobby at Toronto general and talked about it. I said, well, you know what? I'm not going to make the decision for you.

She said, I've done everything in my life that I've wanted to do. This is the one thing that I wanted to do. And I've never been able to do. So I said, [00:16:00] Hey, let me think about it. I thought about it, but a month later I called her and I said, All right. If you really want to do it, we can do this. And so we did the work up that, uh, decision making process, but I mean, my whole thinking as a kid was always, this is my problem.

I don't mind support and help, but I don't want it to affect anybody negatively because I'm already affecting them negatively enough as it is. And I would say, um, when it comes to renal replacement therapy, this nocturnal dialysis program that UHN has, that is. That's like a total game changer. Like when you talk about dialysis, dialysis, meaning you with, you know, peritoneal dialysis or you on a machine.

That's just one aspect of it. But I used to, when I was in university, I had to go in center at Toronto Western, wait and do the evening, get home at like midnight. And I got to get up for class that versus doing it at [00:17:00] home is night and day. Um, and, and also being able to dialyze so frequently versus just three times a week.

So all of a sudden, when I went on this nocturnal program, there's no more diet, I eat and drink as much as I want. Um, you feel good all the time. There's no bad days and, and that's, that's a huge, that's a huge thing. So while the machine, the technology hasn't really improved. In the last 40 years, the way they manage it has improved, and we have one of the best systems in Canada.

Everywhere I travel, when I explain to them how Ontario does nocturnal death, they're, people are blown away. Even at the provinces. When I was in Vancouver, uh, three weeks ago for a conference, and I was at St. Paul's, and they put me on the machine, and they were asking me questions, they said, So, do you have, like, this little machine?

I said, Actually, I got two. The model it's higher than the one I'm using here at my home, right next to my bed. And, um, yeah, we have a, we're very fortunate, very, very [00:18:00] fortunate. I have never taken that for granted. Yeah, the, when I was on dialysis, I did about 5 months in center hemo, and then I switched to home peritoneal and the thing, yeah, what a difference.

And the thing that that stuck out to me was always. The, the goal of the teams was to find what worked best for me and like their, their, um, innovation and, you know, you know, being on top of their toes all the time with the changes in what my machine would tell them and, you know, how my clearance was and just.

Their goal was always to make our journey as easy as it possibly could to be part of our lives rather than taking over our lives. Right. So, I mean, yeah, because if the goal is just to keep us alive, pretty easy to do, but there'd be a lot of miserable people out there. A lot. Yeah, absolutely. You know, I've, I've heard you speak before about your reluctance to talk about your [00:19:00] journey.

And, uh, you know, I'm just wondering why. Why that is to keep that separate. How can I say this? So I mean, I've, I've been volunteering for the keeping foundation for a gazillion years. I was on the board of trillion gift of life network. Um, it's not so much that I was trying to hide it just that the world is funny because I'm in business.

Um, and, and, you know, I have. My family is a supporter. That does guide a lot of my decisions. If at COVID, at the time that COVID started, and that was when I was losing my transplant, if I had come out publicly and done these kind of things and said, you know, I'm getting sicker, I'll be on dialysis in a few months, I can honestly say I would have lost a lot of clients.

People are just that way. And we're, we're human, right? You, you, you, you're working with somebody and they say, listen, Gans, I'm really sick. Well, the last thing you want to do is like, yeah, well, I got another job for you. Right. Yeah, I guess [00:20:00] so, yeah. Maybe I better give this project to someone else. And, but, if I tell you now, and a client says, well, you know, are you okay?

I'll say, listen, I've been sick for three years. I've been on thousands. Did you notice anything? No. So let's get right. So I've always been like that. I will wait for a prescribed amount of time. And then when nobody knows anything, I don't care if you know, because at that point I'll say, if you didn't notice anything in the last two years, you won't notice anything in the future.

As far as living donation. Well, I never spoke about it before because I never had the experience. But honestly, my my eyes completely opened up. So after my mom donated and she was not a young woman, she was already in her late 60s. She recovered very quickly. Um, and her life, her health is fine. So this time around, as I was losing my transplant, um, a client slash friend of mine.

went online and was just doing some research [00:21:00] on me for my company. But then these articles came up saying that I had a transplant. And so she just out of the blue just said, Oh, I read this. Like, how are you? And I'm going to lie to people. I said, well, that part of my life is not great. And she literally just came out and said, you know what?

Like, Can I donate one as I don't just say that, but she was very genuine, you know, I, I, uh, I kind of did what normally the social workers do and I really ran her through the grill and said, look, you have to really know what we're talking about. And she and I had many talks she said this is something I've always.

I've always wanted to do something like this. I think it would add a lot of meaning to my life. And I said, wow, okay. So we talked a lot about it. She's a very dear friend now. And so she's going through the workup. I'm pretty much done. And now we're not a match. So we'll go into the paired kidney exchange.

And see how that goes. But in the meantime, you know, I'm just [00:22:00] doing everything I normally do. And when that happens, it happens. So, you know, you've talked a lot about, um, you know, uh, things that you've been through. And as, as a parent myself, you know, I have a, I have a two year, two and a half year old right now.

She doesn't know the journey that I go through. She doesn't know that I take medication. She doesn't know why sometimes I'm in the hospital or, you know, why I have to have certain procedures. You know, you, you've had this journey with three different kids. Now, do you have any advice for, you know, how we talk to our kids at some point?

Right. Well, I mean, when I was on dialysis, it was, look, I had a massive machine in the room. My girls were young at the time, they clearly saw it, uh, at the time I had a fistula, so they saw me putting needles, I actually showed them how to do it. I said, look, I'm putting the needles in, I didn't want them to be squeamish about blood and needles and everything, because there were always, you know, biohazard bags in my room and having to take them out to the garage and, and I, I feel like when you explain things to kids.[00:23:00]

It lessens the fear. I, I mean, I tried to teach them at a level, maybe a little bit higher than I thought they could handle because I wanted them to understand. I didn't want to sugarcoat anything. Um, and when I went in for my transplant, that part, uh, my daughters didn't fully understand. But they really appreciated when they saw the machine gun, uh, and that was, that was, and then they got it, they got, they couldn't understand why they couldn't just travel with me before and stuff.

And, um, you know, with my son right now, it's kind of the opposite. Well, he sees me on dialysis, but he's never known the transplant side of things. With him, I remember the day the machine was moved in. And he was three and he just popped his head in and thought it was a robot. And, and I didn't, I didn't have time to explain to him.

So I said, yes, it's a robot. And he said, oh, cool. And then he left the room and, and, but now he, he does understand it. And, uh, [00:24:00] and it's great when kids ask questions, you know, because I think that it's, it's important for your kids to fully understand what's going on. I think it, you know, sometimes parents say, well, I'm not going to tell them that I won't scare them.

I think, honestly, I Here's the more if you don't tell them something and then they find out on their own, you know, or, or something bad happens and it just hits them like a brick wall because they had no idea at all, anything, right? You know, it's, there's nothing wrong with, uh, Kids knowing more. I, I, I would feel bad if I kept my kids in the dark, you know, and they didn't know anything.

I feel bad. Also, they wouldn't be very sensitive to you. I mean, imagine if they, if your kids grow up and they don't really know what you're going through and they say something completely insensitive, you know, you, you, and to learn. I always feel like if, if you're a family member and you're going through something, maybe they're not going through the same thing, but at least let them have the benefit of learning from you.

Right? Right. Yeah. That's beautiful. [00:25:00] So before we bring on our next amazing guest, I'm wondering, um, if you have any last advice that you'd like to share for either kids who are going through a health journey or parents of kids who are going through that health journey. I think I've talked about sort of the patient side of things, but as a parent, I've never been a parent, you know, as sick as I've been as a child and seeing my mom go through what she did.

I would be devastated if any of my kids were sick. My kids are all super healthy. I honestly don't even know how I would handle it. Like I get sick to my stomach even when I see my kid hurt himself. So I would say though that as a child and seeing my parents go through it, what My parents did right was, well, number one, they were very supportive and we talked about everything, like literally everything, there was nothing hidden.

And, um, and I think that [00:26:00] is a huge thing for parents to know that, you know, as a parent of a healthy teen, you already don't talk much, so you're in some chronic illness and you might not be communicating at all, right? So I would say that the communication part and, and, you know, Seeing how my parents communicated with me, especially my mother, that's taught me how to communicate with my kids.

That's great advice. Thank you, Justin. Now I'd, uh, I'd like to say thank you so much, Justin, for, for joining us today and for, for sharing your amazing journey and all of this insight, because, uh, there's a lot of people out there who can, who can benefit from hearing about. You know, how you keep yourself positive and, you know, the incredible success that you, that you have in, in your personal life.

And it's amazing being able to hear your journey and see you and your mom and the great actions campaign, because a lot of people are watching you and, you know, cheering [00:27:00] you on. So thank you so much for, for joining us. So I would like to introduce Samantha Anthony. She is a health clinician scientist, transplant and regenerative medicine center, department of social work and child health evaluative sciences and research Institute at SickKids.

Thank you so much for joining us today. Absolutely. Thank you very much for inviting me. Awesome. So I'm wondering if you can tell our listeners a little bit about yourself and specifically why you decided to specialize in social work and pediatric transplantation. That's quite a specific area of focus.

Absolutely. So as you mentioned, I'm a health clinician scientist and social work, and I'm actually that the first and only right now in Canada, so very privileged to hold this position. So with regards to why deciding to pursue a career in social work. I always knew I wanted to work in pediatric health care and social work aligned with my core values.

So think about [00:28:00] respect for the inherent dignity and worth of others pursuit of social justice and service to humanity. As a member of the interprofessional health team, social workers bring a holistic approach to the examination of the biological, psychosocial, spiritual, cultural factors influencing physical and mental health, and also with an emphasis on the social determinants of health and mental health, social workers strive to enhance well being, empower clients, Promote social change and advocate for equity and access to services with regards to transplant.

In all honesty, I kind of fell into transplant. So I didn't have any prior experience or knowledge of the field of transplantation following my graduate training. I applied for a job at sick kids in the nephrology program and then. Had the opportunity to work within renal transplantation. Then I transitioned into the heart transplant program, and now I'm currently working in the lung transplant program.

So, over the last [00:29:00] almost 25 years now, I've definitely grown to be very passionate about the field of transplantation, and As a clinician, what I really like is that patients come to our team with life threatening diseases and all the though the future after transplant can sometimes be uncertain. It's filled with a lot of hope and represents a second chance at life.

And then pediatric quite different from from UHN. Our transplant programs tend to be much smaller in numbers, so we have the opportunity to work very closely with patients and families and develop strong therapeutic relationships that are long lasting. So many of the families that I work with, um, their children refer to our program as infants, and we follow them right until they transition to adult care at 18 years of age.

For sure. So talking about, uh, you know, the child's life and, um, you know, working with children and their families, often we learn about, um, the children's journey through their patient [00:30:00] or through their parents. Sorry. So how do you get to the perspective of, of a child's journey through transplant? And what, um, does that information give you compared to hearing it, you know, secondhand from a parent?

So you're right. Historically, transplant stories have only been captured from the perspective of parents or health care providers. And these have often been, you know, primarily focused on physical functioning and looking at quantitative data. So survival, morbidity, mortality. And as Justin mentioned. We often don't hear the experiences from the child's perspective, with a focus on some of the aspects he had about the psychosocial implications.

So psychological impact, navigating social relationships, especially during those adolescent years. So our within our lab, our overarching goal is to examine those biopsychosocial kind of impacts on patients as well as families to improve health outcomes by [00:31:00] transforming clinical practice. And when you mentioned how we go about that, three kind of overarching aims of our program is to engage patients meaningfully.

So focusing on patient identified priorities and integrating their experiential knowledge through patient centered partnerships. Capturing the patient's voice. So exploring the illness experience from the perspective of those who live it and those who create meaning from it. And lastly, advancing implementation science.

So, promoting the development evaluations, systematic uptake of innovative evidence, informed interventions into clinical practice. And 1 of the things we do, our teams well known for primarily focusing on qualitative research methods. So, really spending time interviewing patients. About their experiences, asking them about what matters most to them.

And again, valuing and trusting their experiences and their stories. Parents again, are pretty [00:32:00] good at assessing physical functioning, but they, they struggle a bit more around understanding the realities of psychological and social relations of the children. So again, their assessments are incredibly valuable, important, but It does make a big difference when you actually turn to the children themselves about what matters most to them and then having that information influence care, right?

And the plan of care. Yeah, like Justin said, um, you know, with teenagers, we often, uh, get one word answers out of them, you know, how was your day good? What did you do today? Nothing. Right. So, and getting to have a team like yours to actually explore what is going on from their perspective and sit down with them and take the time to really have them open up, I'm sure is quite valuable to know.

from, from a social work perspective and just a holistic approach [00:33:00] as well, right? Because we know at UHN and at SickKids in many places, we're not just treating the symptoms or the disease. We're trying to treat the whole person as the journey that they're going through instead of, as we talked about, just their physical body.

Exactly. Exactly. Yeah. We've recently, our team has created a electronic patient report outcome measure platform called Voxie. And one of the objectives aligns with What you're talking about how difficult it sometimes is to engage patients in conversation. This allows patients the opportunity to complete outcome measures, looking at domains of function that are important to them.

These outcome measures in advance of clinic. And it's on a, an app that was developed by patients for patients. So it's very kid friendly. So it's what, you know, gifts integrated throughout to encourage them to share their voice and perspectives. So it's a way to, again, when they come to clinic, we have some data that they've already [00:34:00] shared that we can use as a springboard for engaging them in conversations about how they're doing.

Because again, when they come to clinic. Exactly. Like you mentioned earlier, how are you doing? Fine. How's school? Good. Right. Right. You need that element of curiosity and to probe a bit further. And we were quite surprised. Actually, a lot of the interviews we do, we think they'll be difficult to engage once they get going.

People often want to share their stories and they find by sharing their stories. It's actually therapeutic in of itself, and even as, as Justin mentioned earlier, many of the patients that we work with haven't met other patients who have undergone transplantation. So to have opportunity to potentially share their experiences where it might benefit others is meaningful to patients.

So sharing some of the more difficult. You know, areas that they've had to navigate, um, as well as even what Justin mentioned, some of, um, strengths [00:35:00] highlights. Um, I think often we focus on the negative aspects, but many of these patients do talk about, um, many of the benefits. I'm undergoing transportation, so being able to talk to somebody who.

Has this as a strength or an app where, you know, we can quietly do this by ourselves rather than have to engage in an open up with a bunch of people might be a safer way for people to do it. And even the, the study participants have talked about the fact when you come to clinic, you're in a very different head space.

You might be undergoing different tests and procedures that day. You might've had to get up early to, to get to the hospital that you're being cared for at. So if they have time to reflect in advance, Wow. So transitioning from, from SickKids to UHN or other adult centers is, is a huge life event for most patients.

How do you prepare patients and families for that journey of leaving, you know, [00:36:00] the cozy home that is SickKids to, to going out into the big wide world? To write it definitely is a, uh, as I mentioned earlier, like a pivotal stage in the ongoing management of transplant recipients and not an easy one. So from a clinical perspective, I think what's important is that transition planning is recommended to begin an early age.

So usually around the age of 12 and really focusing on creasing the independence, knowledge and involvement of the adolescent in their own care in order to equip them better for the adult care system. Many years ago, we actually conducted a study. It was published in the American Journal of Transplantation, where we asked patients and and parents about what, what were their needs around transition.

And they definitely mentioned, you know, ongoing communication and collaboration between the pediatric and the adult practitioners. So, again, they recommended a cohesive transition plan that there potentially could be joint visits. Between the pediatric practitioners and the adult practitioners, at least [00:37:00] for initial period of time.

The other thing as a, as a scientist that we're currently investigating again, which aligns with with Justin's experience is looking at the implementation and evaluation of mentorship programs. Really important, um, both for mentees and for mentors. So we've recently implemented an online peer support mentorship program.

That provides modeling and reinforcement by young adults who have recently transitioned. So those between the ages of 18 and 24, and they are mentoring adolescents between the ages of 12 and 17. So, again, our findings have been. Phenomenal. The impact of this program, the program addresses feelings of isolation, fosters a sense of connectedness and understanding.

And again, as I mentioned earlier, hearing the stories of someone else who's been through a similar journey offers reassurance, encouragement, as well as hope. Amazing. I'm wondering Justin, if you think, you know, if [00:38:00] you back back then would have had access to something like that, a mentorship program, if you think that would have helped?

I would say, honestly, the biggest shock for me was actually, um, when I had to go and stay as an inpatient. So being an inpatient as a kid, and then the first time I stayed as the inpatient at TGH, I was like, Oh, okay, this is, this is different. Um, No, because they, they, just the way the nurses and doctors are trained to talk to kids.

And it's, it's very different. I would say that was probably the biggest shock for me. Um, but, um, when I was part of the program at sick kids there, we had social workers that, um, meet, they asked us to do lots of group activities, actually. Um, that was a way for us to meet other patients who are our age.

And a lot of people, especially parents, they feel isolated. They don't know who to talk to. And not everybody's that. Social, they won't, you know, at clinic, they won't turn to another [00:39:00] parent and say, hi. So the social workers back then create a lot of opportunities for us. You know, we go to parks and have picnics.

And so we got to talk to each other and it gave us a resource. So I had a, you know, in my phone book, I had a whole list of kids that I could call if I, you know, had a question or something. I remember there was one guy who transferred to, um, adult hospital a year before me. So I did actually speak to him a lot after.

So that might've been why it wasn't such a brutal transition. When I moved over, I had him to talk to. Yeah. The other, I can't remember, Justin, did you mention you had gone to camp or no? Yeah, I went to, uh, a, uh, I guess it was back then it was called camp dialysis. It was up in Halliburton and we rented a camp along with hemophiliacs and asthmatics.

So there were transplant dialysis, hemophiliacs and asthmatics. We were all at camp at the same time. And it was probably, it was only one summer and it was the best summer. Honestly, I remember every part of that camp. It was the best experience of my life. [00:40:00] Because after my transplant, I felt like I didn't necessarily fit in at school anymore.

I remember because I went away, came back three months later, and all of a sudden everybody was taller than me at school. And I really felt out of place. So when I went to that camp, it was just like a very safe environment. It was great. That was run by the kidney foundation. That really was a great experience.

Yeah, I think I always encourage people get involved if the program's there, it's there for a reason. So do it camp. I think it's an amazing intervention. Um, and, and definitely would be one of the. The psychosocial supports that helps around transition and feeling connected to peers. I think one of the things that we notice outside of renal transplant, we have smaller numbers, say in, in heart and lung that often these patients live in very remote regions of Canada.

So one of the nice thing of the mentorship program, it's all online. So really thinking about how to use technology. That's been really [00:41:00] helpful, especially, you know, just coming out of the last. three, four years of the pandemic about the added isolation for patients. And the increasing kind of concern around mental health issues has definitely led us to kind of look at different interventions on how best to support patients and families.

And Justin and I, you know, we, we talked about kids and our parents and, you know, all of the people that are part of. Our, our journey as much as we're the ones who go through it. It really does impact the whole family and, and everyone who's around us. So I'm wondering as a social worker in your role, how do you support that whole family journey?

And do you have any advice for that family journey that they're going through at SickKids? The parent's quality of life is definitely impacted by the mounting demands and stressors associated with their child's chronic illness, and research has demonstrated clinically [00:42:00] significant levels of psychosocial risk for poor mental health outcomes, and the health of caregivers also impacts family functioning and patient's health outcomes, so really it's the kids mindful of providing family centered care.

So thrilled that, as I mentioned earlier, the iPeer2Peer program that we launched, we've now expanded it to the iParent2Parent support group. So we're just getting ready to launch this. Again, very mindful of, as you mentioned, the impact on parents. And we also have recently had funding from the SickKidsLabatt Family Heart Centre.

And we recently piloted a mindfulness based retreat as an intervention to enhance community building, mental health, and quality of life amongst mothers of heart transplant recipients. And findings have supported that this retreat has been an impactful intervention. And next steps would include investigating potential expansion of the program to other clinical populations, including You know, other caregivers.

So when we actually [00:43:00] did the recruitment for the study and we were inviting mothers, often the fathers were saying, and what about us? I think they often do get forgotten. Um, And as well as siblings, so very mindful of that's another group. That's really important within the circle of care to their perspectives.

What's the impact and supporting them throughout the journey? All of the research we have. We work with patient partners. It's patient oriented research. One of the benefits of being a health clinician scientist is that I still am involved as a clinician. So I work very closely with patients and families and they share with me their concerns and their needs, which guides the research that we do.

And so I kind of step away from my clinical practice, do some of the research and evaluation, and then can readily translate the knowledge back into policy and practice. Fairly seamlessly, because that's what I do, um, just really the benefit of, of these health clinician scientists roles within [00:44:00] healthcare.

Yeah, that is so unique to be able to do that. So, you know, often with a, with a health journey, we, we focus on the, the negative things that can happen and, and, you know, what we go through, um, but there is this concept of, of post traumatic growth. Can you talk to us a little bit about that and, uh, you know, how that impacts transplant patients or people who have been through a health journey like this?

So absolutely. So the concept of post traumatic growth has been around for a long time, and really within the field of transplantation, it stemmed from my, my PhD research, where we interviewed adolescent heart and lung transplant recipients. And their narratives started to illuminate themes that aligned with post traumatic growth.

So some of the themes that emerged from those interviews were awareness of personal strengths and coping abilities. You know, courage and [00:45:00] confidence to explore new opportunities following transplant, they spoke about relationship growth. So a greater appreciation for family and friends, uh, more meaningful time together.

They also spoke about kind of this introspective growth. So the sense of self, so developing a different, and maybe this is when Justin talked about kind of life philosophy, this increased gratitude for life, living life more purposefully. And when we spoke to the kids, I remember interviewing them. They seemed mature beyond their years.

So this, you know, overall transformative experience, the changes that happened, not only physically, but emotionally, spiritually, and socially, and they, one of the adolescents spoke about kind of a transplanted self. Oh, I like transplant. Exactly. Um, that transplantations can be viewed as a catalyst for positive growth and personal change.

So, as you mentioned, I think we often focus on. The negatives of the problems associated with transplantation. I [00:46:00] think this is a very different approach to very strength based with regards to, to practicing as a, as a clinician, it's, it's a very positive way to think about, you know, some of the. More difficult days that we've had in our lives to, to look inward and think about what the growth has been one thing that borders on cliche, but one thing that I'm very aware of is that anytime there's been a horrible period in my life.

It never lasts. And every time there's a great period of my life, it never lasts. So I try, even when things are bad, I've actually kind of trained myself to absorb just how bad it is. Like, I remember there was a time I was in the hospital or by me, there'll be horrible, but it was particularly horrible and it was miserable.

It was, it was winter out. It was depressing and hot in [00:47:00] the hospital. And I just said, you know, I'm just going to absorb. Just how gross this is so that when things become good again, I'm going to enjoy it so much. And, and that's just, that's how I've grown really, um, through the experiences. And yeah, cause you know, when I was a kid, I used to say, Oh, I wish this never happened to me, but as an adult, I've never once said that I've never, Once questions fairness, or why did this happen to be everything I I'm I'm actually really glad I did so, Samantha, um, you know, we've, we've talked a lot about, uh, different aspects of, of the, uh, you know, medical journey and your perspective with your team.

Um, what's, what's next for, for your team. I think right now, definitely looking at technology. So we're, we have some new funding looking at AI. Again, we're looking at implementing Voxy. Voxy has been selected as the [00:48:00] platform for the SickKids Mental Health Strategy here at SickKids. We also have an approach from many other institutions, as well as actually adult centers around potentially implementing Voxy 2.

0 at an adult site. I think continuing to explore the experiences of families, looking at creative interventions to support families, that's always, again, the heart of what we do. When you talk about like mentorship programs, um, and

things like that, do you, do people self identify and say, I, I need to talk to somebody or, or do you, is this, is what you do, is that offered to?

Both. Both. And a lot of it right now, it's, it's often very difficult to, to implement clinical programs without evidence. So I think what we've been very fortunate of is that we've been able to secure funding, implement and evaluate the program, show that it's effective, And the impact it has on patients and families and then [00:49:00] move towards clinical implementation.

So that's kind of when you ask what's next. I think we have these amazing programs. It's now translating into practice and that's some of the work we're doing right now within the institution. But again, want this to be available to everyone. Um, I find often within research, you do get, you know, A very similar population who has the time and volunteers to do research, and we really want to target, you know, patients and families whose, you know, whose voices are often not heard.

So, a lot of the research now looking at how can we implement these programs in different languages, right? Um, being mindful of. indigenous health and incorporating lessons and learnings from different communities into our programs, diversifying our patient partners who are advising us around directions that we need to be taking as researchers.

So that's some of the work that we're doing at the present time. Yeah. Just a [00:50:00] thank you to all of the social workers, to yourself and you know, all of those people who support us through, through our journey. Well, thanks so much. I'm really glad that, that, um, the pro these social programs have. They have, uh, evolved, you know, because I remember, you know, back in the early eighties, uh, there were many times I would voice certain things that were not medically important.

Right. And all I would, all I would hear is, look, your blood work looks fine. So right. Right. And I'd be like, yeah, but I look horrible, you know, how am I going to fix all this? And um, and, and, and I had to solve all these problems on my own. And I just really liked that. That everybody that the community is listening to patients and, and, um, and that it's evolving because especially for kids, it was so hard, like it was, it was so tough.

And when I look back. Yeah, 90 percent of the problems I had had nothing to do with the actual kidney disease itself, and I everything to do with the social problems that [00:51:00] created medication side effects lifestyle being impeded like everything was, it was all the packaging around it. It was, it was actually the biggest problem.

Absolutely. Well, thank you so much, Samantha, for joining on us on the podcast today. We're so grateful to have you and for all of the incredible work that you continue to do. And if people want to learn more, I will put a link in our, um, information as well. And Justin, as always, it's always a pleasure to, to chat with you and get time with you.

Thank you both so much. Take care. Thank you. We hope you enjoyed this episode of the Living Transplant podcast. If you did, please leave us a review and share with your friends. Don't forget to subscribe to Living Transplant wherever you are listening today. If you have any ideas for podcast episodes, you can reach out to us at livingorgandonation at uhn.

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