

Season 4 Episode 5: I've Learned to Walk 3x in My Life

Candice Coghlan: [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 Shilpa Raju.

An epidemiologist who finished her degree while battling cancer. She survived the cancer, but the side effects from her treatment caused severe lung damage resulting in her need for a double lung transplant. Shilpa spoke to me about being a young person battling illness and trying to keep a sense of normalcy and positivity through her day.

Later, we're joined by Dr. Mamatha Bhat, a staff hepatologist and clinical scientist at UHN's Multi Organ Transplant Program and U of T's Division of Gastroenterology. She speaks to us about machine learning and AI implications for healthcare and how it is going to revolutionize the world of transplant and beyond.

Please enjoy. Welcome back to the Living Transplant podcast. I am [00:01:00] so thrilled to have Shilpa with me today. Thank you so much for joining

Shilpa Raju: me. Thanks for having me, Candice.

Candice Coghlan: I'm really excited to have this conversation today. I'm wondering if you can tell our listeners a little bit

Shilpa Raju: about yourself. Okay. So my name is Shilpa Raju.

I'm a double lung transplant recipient. I received my transplant, um, about 10 and a half years ago. And in my non patient life, I work as an epidemiologist. I work with public health and I've been doing this, um, for 15 years now, probably. Yep. And, uh, and then other than transplant and work, I love to eat. I love to travel.

I love finding new things to do. I was born and raised in Toronto and I still live here currently.

Candice Coghlan: Interesting. That's very cool. And so, um, you said a little bit about this in your intro, um, but I'm wondering if you can bring us down that [00:02:00] path of how you became a double lung transplant recipient.

Shilpa Raju: So in the last year of my undergrad, um, I was diagnosed with Hodgkin's lymphoma.

And, um, from a cancer standpoint, it's a pretty treatable, curable cancer. And they do see it in younger people. So it's one of those that with a pretty high remission rate and the treatment they know to be quite successful and in many patients. So I was doing chemo and radiation for the lymphoma. And unfortunately, one of the known side effects, which is the case with many, many of these sort of the illness, but there may be some other unintended consequences or side effects.

And so with one of the meds, in the chemo regimen, uh, one of the known side effects is pulmonary toxicity. And so with that, it started to damage my lungs quite, quite rapidly, I think, while also treating the cancer. [00:03:00] And I started to notice this first because I am, as I used to sing as well as dance, and I noticed, you know, I was getting much more out of breath as the treatment was progressing and, and they recognized, okay, it might be due to this medication.

So they were able to pull it sort of toward the end of treatment, um, which may have slowed it down a little, but I also needed radiation just because of the stage and the progression of the cancer when it was first diagnosed. And so I think between the chemo and the radiation treatment, um, my lungs went through quite a bit of scarring, which may have been more than they would have normally expected.

And so over time, my lung function had dropped quite significantly, like by the end of even just the chemo and radiation, I was already down to about 25% of normal lung function. And so for the number of years kind of following, it was just sort of trying to maintain, but eventually two, three years. And actually, yeah, probably three years out from when I [00:04:00] finished treatment, it got to the point where, okay, I'm like exhausted doing any activities of, you know, daily living.

I can't walk from like kitchen to bathroom or bedroom to bathroom without just being very short of breath. And, and at that point, um, the physicians that I was seeing here at Toronto General suggested, you know, maybe I should be using oxygen to help feel less, um, short of breath when I'm, when I'm, um, doing, you know, basic things and then over at that point also is kind of like, okay,

well, maybe it's also a good time to start discussing other alternatives, seeing the progression of the lung disease.

Yeah. And so that's sort of when, when the discussion around transplant also started to move its way forward. So

Candice Coghlan: how many years did you live with that reduced function before they talked about transplant?

Shilpa Raju: The, the, the conversation on oxygen, I think started in probably around November, 2010, the physician suggested, you know, maybe we [00:05:00] start to get you on supplementary oxygen.

And around that time also was like, okay, should we start talking about transplant? So three years, I guess. You sort of learn to adapt to what you have, and you don't always realize how much you're pushing beyond what's normal, just to kind of keep yourself going or doing the things that are not quote unquote normal.

And so I think I was really pushing myself in those couple of years that followed. Just saying, okay, this is the new normal. I'm going to be a little shorter breath doing these things, but I can still do them. So just keep going. And I've talked to

Candice Coghlan: so many people who have a chronic illness or chronic disease.

Um, and with that, like you said, with creating your new normal and just like pushing through, because you have so many things that you want to do and busy and you're trying to achieve these things as a young person.

Shilpa Raju: Like when I was diagnosed, it was the end of my first semester of my last year [00:06:00] of undergrad.

So at that point I was like, I am ready to start. Like this is, you know, when your life starts, at least when you're at that age, that's what it feels like. And just like, I just. I have to finish this degree. And so that whole last semester I was doing chemo and like sessions every two weeks and still finishing my courses.

And first I didn't want to tell the faculty that I was going through this because I, I just had this perception that they would be like, okay, you should not be doing school. Like you should be stopping. And I was very like, no, I'm on my

schedule to like finish this thing. And I didn't tell them until I like passed out in the class.

Someone was like, okay, maybe this is a conversation. And, you know, once I did have the conversation, they were very supportive and like, very, you know, like they understood my goals and we're working to help me like get, you know, to finish. And there's this need to prove yourself. I felt very much a need to prove myself.

Like even recognizing, you know, I've at that [00:07:00] point that even just the cancer. Cancer treatment. It's already you, you, there's like this feeling of like, you know, your trajectory is now it's a little bit different than your peers. Um, but then, you know, there's some part of me that also thinks like some of that must have been helpful because I, I see that those steps that I took, you know, Maybe a little bit impulsively, maybe a little bit crazily, but those pieces helped set me up for, you know, leading up to transplant when I finished my degree, I was still able to work in the field that I had studied to work in.

Candice Coghlan: When your team discussed, um, transplant, what did they say to you that the timelines and how this would affect you and were you accepting of? Is that it? At the beginning,

Shilpa Raju: I think, you know, honestly, after the cancer diagnosis, I remember being like, Oh, yeah, like, there's a feeling of like, okay, I'm going to get through this, like, it's going to be fine.

And it [00:08:00] was from one perspective. And then with transplant, I think there was a feeling of okay, this is like a lot bigger. But at that point to maybe what's different a little bit from for with the lung transplant and probably for some of the other words to is like, There is no alternative. Like at that point, when they're discussing this with you, when they're saying, Hey, we should start assessing you.

It's because they're looking out ahead and saying, you know, you don't really have any other options. We can't, it's a bit different. Now I'm seeing with kidneys, like, you know, you can be on dialysis and that can prolong your weight, but with lungs, I think they're very careful about determining what time to list you there.

They want to minimize your risks and maximize the benefits in the The frame of those risks too, because transplant itself, the surgery is a huge risk. All the pieces that come with the transplant, you know, the immunosuppression, that

doesn't come without its own bag of side effects and other life, you know, things to potentially [00:09:00] deal with, which I am.

Dealing with now. And so, you know, you, you see all of that, but then you also are confronted with, well, this is your last resort. Like it's either this or that's kind of the end of the road for you. And so I think once you sort of. With lungs anyway, when you sort of think about that, then it just like, well, this is what I have to do.

So now, how am I going to make this work? Like, what are the pieces I need to do to at least hope for the best outcome? And I think the lung transplant program at UHN, and the one really nice part about it is the, um, Difficult at the time, but really important part of the program is when you're listed for transplant, you also have to participate in a prehabilitation program.

So you have to come into TGH three times a week. Now, I know this may have changed what that looks like, depending on where you live and stuff now, but 10 years ago, you had to be close to the hospital. You had to be [00:10:00] able to come in three times a week for exercise. Uh, to kind of just be able, nothing fancy, but more just to, you know, maintain whatever function you are able to with your muscles, keep the strength that you have, because recognizing that the operation itself is going to be a huge toll on your body and that recovery is going to look so different for so many people.

So that's like the very medical reason for being there. But what I hadn't anticipated was how important that was for building community with other patients. And The piece, you know, when you're there three times a week with the same people who are also coming, you start to build up with each other. And then we started planning like, you know, games nights once a month or like outings.

We would go to a movie theater to watch a movie and there would be five of us with our oxygen tanks and walkers and our support people. And the feeling of this being something you're going through alone, kind of like it, it didn't, it just sort of starts to like. [00:11:00] Make that a little bit easier recognizing, you know, like I did have a lot of support from my friends and family, but it's still a very strange experience, right?

Like being like, you still, again, feel that sense of different from your peers and different from, from everyone who's sort of in your community. I think that's where this community was kind of like another, um, aspect of that. Um, and so with that, and also my mom being. Um, it was hard for me to have that

dedicated support person because all this stuff, unfortunately, happens during work hours, which is really challenging also sidebar that as a patient, but like all these things assume that your, your whole life is consumed by being a patient.

Everything is during like. Work hours or, you know, eight to four so your whole job is to be available at a moment's notice or like on the schedule of the medical system, and it doesn't really leave a lot of room for patients to have. You can't have normal lives outside of it because [00:12:00] you're constantly at the whim of whatever schedule exists.

So that aside, because I had to have someone come with me, um, to all these appointments, physio, um, and I couldn't have one person. My friends suggested an idea of having a Google calendar and like, basically it was a rotating door of friends. And everyone just signed up when they could take an hour off work, especially for the friends who work downtown.

And it was a really. Great way of maintaining those close friendships that were mine outside of transplant world too, because they would come in. I would just be like, I can't really talk. I'm really tired. I need to do the thing. But tell me about your life. It didn't feel so Um, I think once I was listed, you just kind of going through all the motions of daily life.

I don't think I really had a feeling of like, when will my time come? I also had five or false calls where I was called in the organs in the end and being good to transplant. So was it call number five? [00:13:00] Sorry.

Candice Coghlan: Yeah. Number five. That was the, the actual, the actual call. And when you got that call five, were you like, here's another drive?

Yeah,

Shilpa Raju: honestly, I was on a three way call with two of my best friends. We were just talking about other stuff. And then I was like, I saw the no caller ID on my phone, like come through. I'm like, okay, that could be a hospital. So I remember going off and then getting back on the phone with them and being like, Oh, just got a call heading to the hospital.

But like, you know, by that point it was like, okay, it's probably not going to go happen again. And, um, got to the hospital. My sister came with me and fell asleep probably maybe after midnight. And I remember waking up to a man. with a stretcher, uh, my, in the, like, the, where they, where you go to wait while you're waiting to hear whether the organs ago.

And in the room, this man shows up with a stretcher and he's like, okay, we're taking you down. And I was like, Oh, what? Cause that's the first time it had been. anything beyond the [00:14:00] waiting in a call in the weight room. And so, yeah, then I told my sister, I'm like, okay, call mom. Cause now it looks like it's, it's at least moving past this step.

And then, yeah, we went down to the waiting, like the pre op area. Yeah. I don't think it was much longer. And then someone came to take me in and I was like, I remember, like, looking at my mom and sister, like, my mom looks terrified, just kind of, you know, like, nervous, and I remember saying, okay, like, don't worry, you know, like, I'll be back.

It's going to be fine. And I think I really believed going in, it was going to be uneventful because The reason I needed the transplant wasn't what was typical for most younger people who tend to have cystic fibrosis, and I wasn't older, so like, from an age perspective, you know, I was like, I just can't, like, the thing that I have is just a lot of scar tissue, like, um, and hopefully being younger means that my recovery will be a little bit easier, and that's kind of what I, like, Naively thought going in.

Um,

Candice Coghlan: and then your, your [00:15:00] journey post, how did the lung transplant impact your, your life?

Shilpa Raju: Yeah. So the first year was quite rough. Um, because again, like I, the operation. Ended up being a lot more challenging than they had expected. I think there was a lot of scar tissue. It took a lot more effort to get the lungs out because there's a lot of bleeding.

And then also, um, even just getting the new lungs in, I think size wise, they were big. I'm quite a petite person and I think there were a lot of challenges just operationally as well. And then my body's response to it, the transplant, I think it just didn't handle it. Really, really well. So, um, so at that point, I was just like getting up and like learning to walk again.

I hadn't eaten and so like learning to swallow being able to do that safely before you can start eating real food and not just through a tube. And, and then another month in the hospital post the ICU, [00:16:00] just to sort of recover build back strength, be able to. Leave the hospital and be safe. And that was quite challenging.

And then, you know, back out into the outside world, starting to get back into a routine. And another one of the complications with transplant and transplant medication. Um, if your body is like, You need a certain level of immunosuppression to not reject the new organs, but there is a balance if you're also over immunosuppressed, then your body's immune system doesn't work in the way that it should also to suppress things like tumors from going out of control.

And so one of the. Challenges I had was I ended up developing a post-transplant type of lymphoma that we're at higher risk for, and with that as well as a few other infections. Um, basically ended up back in the ICU for another two months. And again, you know, lose the ability to speak, lose the ability to walk, lose the ability to eat all of that again for another two months.[00:17:00]

Uh, and then another two months after that, again, recovering learning like I now I. Reflecting back at a time thinking I've learned to walk three times in my life. Most of us can't even remember the first time we learned to walk because you're so little. Um, and so the first year was very, this all was in the first year for like a number of years, probably about eight years.

I didn't have any challenges like I was not admitted I barely got an infection like I was, you know, back to normal life back to working back like in office, having a normal social life traveling, what I didn't notice my, I was starting to have difficulties breathing and as that was. I think we just assumed it was long related because you know, again, I didn't have that much reserve.

It could be rejection. It could be just, you know, this is maybe inevitable. Like, your, your, your transplant will start to fail at some point. And then. It turned out through various [00:18:00] series of events, we, we found it was actually my kidneys and my kidneys had been really struggling and were at this point become so damaged by, um, like the side effect, I guess, one side effect of maintaining those lungs, the anti rejection medication.

I was already at stage four kidney disease when they discovered it. And just as we were sort of processing, okay, that's, you know, that's where you're at. And at that time, Based on my personal numbers, what they were saying was, you know, it looks like, you know, there's like a 20% chance in the next couple of years, you're going to need dialysis or transplant.

But right now, you don't have that many symptoms, I guess, once they've gotten the blood pressure piece under control. Um, you don't have any symptoms, so maybe, you know, maybe, maybe it'll be a couple of years, maybe it'll be longer.

Uh, but what we didn't know at the time, I developed another pneumonia that post transplant patients are a little bit higher risk for.

And unfortunately, that the... Treatment for that particular infection is also [00:19:00] highly nephrotoxic. And so whatever little function reserve I had left in the kidneys just kind of took a hit. Um, and unfortunately it was one of those like sacrifice the kidney to save the lung situations. And so, so I started on dialysis right away in hospital while I was admitted to treat the pneumonia.

And, and then, yeah, since then, so this was March 2021. And, um, I've been on dialysis since

Candice Coghlan: I read an article where you, where you spoke about your mom's journey as well. Um, if you're comfortable, I'm wondering if you could speak a little bit about transplant in the South Asian population and, and what that journey was like for, for your mom and your family.

Shilpa Raju: It's funny growing up. She always told us when I go donate all my organs, donate my body to science, like this was something she very strongly believed in. I think where the challenge came up with her was around the actual [00:20:00] medical side of the transplant and me being that recipient and all of the challenges that would come with it.

That to be fair to her as well, kind of everything they did sort of Lauren might happen could happen did happen. And, and so she wasn't entirely baseless in her fears for what that might look like for me as a patient as her daughter and what that might mean for my quality of life. But I think once you also saw, I mean, again, the first.

First year was very challenging. She was still there for it, and of course supported me in all the ways that, you know, my mom did, would. Um, and But, you know, since then, as she saw how much more my life returned back to, you know, normal, I keep using the word normal, but what feels like normal to most people, um, I think she's seen how, how amazing some of the things I've been able to do are.

And now taking it back to the South Asian community at [00:21:00] large. I think just like other ethnic groups, you know, the need is there, the need for transplant is not something that discriminates based on race or ethnicity or religion and but people just might be less comfortable discussing topics like cancer, transplant, or even serious illness like I feel like There's sometimes a reluctance, um, to rely on community at large for some of these things.

It's kind of like, Oh, this is more of a personal matter. But I've also seen, you know, when the conversation happens, the way that communities actually rally for each other is quite remarkable. It's like I know a big thing that was a source of support for my mom when I was going through transplant and having all those complications in the ICU and in hospital.

I think, you know, Her temple community, they would do maybe an extra prayer or people just saying, you know, we're thinking of you. I think those things. It's also add a lot of support. It's why it's so important for recipients like myself, who are visible minorities, who do come from diverse backgrounds to share those [00:22:00] stories, to speak about the transformative impact of organ donation and transplant on our lives.

Because when people can start to see themselves, their kids, their parents in people like us, I think it. And it starts to feel real.

Candice Coghlan: So I'm wondering if there's any advice you have for people who have been recently diagnosed with a chronic illness or disease, or, you know, just are having a difficult time even in in how to manage this and and get through day to day because you're such a light and a positive person to get to meet.

So I'm wondering if you have any advice for those people out there.

You're

Shilpa Raju: so kind first of all to say that, but on the note of kindness, you know, be kind to yourself, recognize there's going to be good and bad days. You just do what you can get through it like one day at a time. I think for me, a big part of that is also learning about the condition in a way that speaks to me.

So for me, [00:23:00] knowledge was power and like being able to understand what this looks like, what, and knowing how to manage that condition, I think helped maximize what I And how it's able to live and then also within the, um, context of some of those changes that are continuing to happen and some of the constraints, but I feel like being educated about it was empowering for me.

Um, and then recognize that also your, your journey is going to be different.

Um, I think it's one thing to ask other patients about experience or tips with something to help understand what you're going through. But if it's different from what you're going through, that's okay too. Um, so don't feel that pressure

that like, okay, it looks so different. Um, maybe this is, you know, the, maybe I'm doing something wrong.

Maybe all those assumptions, like I think just treat your journey as your own and get the help sort of where you can to understand what this looks like big picture. And then maybe the [00:24:00] last, I don't know, last thing or another really important piece I feel like is, um, support. So find out who those people are for you and lean on them when you need to, because it could be a friend, it could be a partner, it could be other patients.

Um, and then you may lean on people for different things, like non patients may not understand the ins and outs of exactly what you're going through. Cause I mean, for you and I too, like we're both. Pretty young. Um, this is not normal for most young people, most like new couples or even just like people finishing university are not sitting there thinking about, geez, how am I going to manage chemo this week or how am I going to manage through dialysis?

I'm so tired, but I got to go into the office tomorrow anyway and make an appearance like These things are not, no, or I'm going

Candice Coghlan: to go to my friend's birthday party tonight. How do I tuck my hemo catheter, my catheter into my outfit? So they don't see, I have two tubes going to a [00:25:00] party. So it is now my pleasure to have Dr.

Mamatha Bhat join us. She is a staff hepatologist and clinician scientist at UHN's multi organ transplant program and U of T's division of gastroenterology. Thank you so much for joining us today.

Dr. Mamatha Bhat: Well, thank you so much, Candice, for the invitation to join you today. It's really my pleasure, uh, to talk about AI and transplantation.

Incredible.

Candice Coghlan: So before we get into that, uh, fascinating work that you're doing, I'm wondering if you could tell us a little bit about yourself and what led you to become a hepatologist and specifically in transplant? Yeah.

Dr. Mamatha Bhat: So my interest in liver disease and liver physiology really started as a medical student.

Additionally, I was fascinated by the complexity of the liver as our metabolic factory and how its roles are so [00:26:00] complex that we don't have the

ability to replace them with machines. So, uh, I just found the organ very fascinating. And then beyond that, I was really inspired in, um, you know, interacting with patients who had liver disease.

And I also remember as a resident. Seeing the impact of liver transplantation in a patient who had in stage liver disease. So I think all of those factors together, uh, you know, having inspiring mentors interacting with patients who also were inspiring led me towards this particular career pathway.

Amazing.

Candice Coghlan: Um, and I'm wondering if you can speak a little bit about that work that you're doing in improving long term outcomes after liver transplant. So, if you look at the

Dr. Mamatha Bhat: last 30 years, we've had significant improvements in one year survival. So, uh, from 65% to [00:27:00] 95% one year survival, but if you look at the survival beyond a year post transplant, that has not improved in the last 30 years.

So, there is a study that showed that a few years ago. And, uh, data like that, or studies like that, inspired me to, and also my own experience seeing patients who were developing these complications, uh, after transplant, inspired me to opt, try to optimize outcomes, and not just by looking at clinical and laboratory data that we were collecting, but also understanding what are the mechanisms, like what are the genes, what are the, you know, pathways that are affected, and how can we optimally treat patients who have these complications so that they can enjoy.

their second life and enjoy the best possible lifespan after a transplant. So the reality is that [00:28:00] those complications include a higher risk of cancer, higher risk of heart and kidney disease, infection, as well as graft failure. Graft failure means failure of the transplanted organ. So those are the major issues that compromise long term survival.

And we don't have a good understanding Of what exactly drives those complications in the long term. So how can we better understand those and then personalize the care of transplant recipients who develop these

Shilpa Raju: complications? I was also thinking about what you were saying related to improving the outcomes or even just studying what it looks like, what survival looks like after a year.

And I think one of the pieces you mentioned with the clinical and the, I guess like the biological, yeah, biological things that we screen and test for, but I think another area that hopefully has more growth and maybe you can comment on this too [00:29:00] going forward is also Beyond those types of metrics, what does quality of life look like as well?

Because the number of years, if you're alive 10 years and, you know, struggling with so many things in that 10 years, how does that get captured and accounted for and improved when we think about patient outcomes, um, beyond, uh, the, the extent of life or the quantity of life extension?

Dr. Mamatha Bhat: Yeah, that's an excellent point.

And, uh, I think certainly Um, helping to optimize the care of these different conditions will then enhance the quality of life. And certainly, uh, we have colleagues who study the quality of life measures, and I think, you know, with tools of artificial intelligence, there is certainly, um, you know, great potential to integrate these diverse types of data.

Understand how they are [00:30:00] affecting not only quantity of life, but also quality of life. And how can we modify those, you know, different factors that are affecting both of those aspects so that we can enhance long term outcomes from that quality of life perspective as well.

Candice Coghlan: Fantastic. So you brought up that, um, AI implication.

I'm wondering if, if we can discuss a little bit about that machine learning and, uh, AI implications for healthcare, um, that, that you've been working on.

Dr. Mamatha Bhat: So artificial intelligence, uh, refers to various types of tools that can learn patterns and learn hidden interrelationships between different types of data.

To then. Personalize prediction, personalize prediction of outcomes, personalize. You know, um, diagnosis treatment on the basis of all those [00:31:00] different data points that a particular patient has in their history and the nice, the very interesting thing. about artificial intelligence applications and transplant, I think is because transplant medicine is so complex.

So we have so many different types of factors that will affect long term survival or short term survival. Uh, you also have applications and donor recipient matching prioritization on the waiting list. There are certainly You know,

different avenues for growth. Uh, and there are these different applications that I think are so complex that it is difficult, certainly for the human brain to assimilate these hundreds of variables, these hundreds of data points over time to provide predictions.

We have our own intuitive predictions, but [00:32:00] I think that with machine learning tools. There's a great opportunity to decipher that complexity and leverage those longitudinal changes to obtain personalized predictions for a given patient. Now, I would say that to develop a machine learning model in transplant is not easy because there's so much complexity there.

And it's very possible that say, if you just trained an off the shelf machine learning tool, you may, you might not be able to transfer whatever you learn from a large data set to your institutional data set. And then it's important to understand what are the factors that are causing this decreased performance in this particular data set, and how could I improve the performance of this algorithm.

So in our case, in my team's case, we have actually developed new methods, so new machine learning methods designed for the [00:33:00] specific liver transplant question. So, this involves very active crosstalk with computer science professors. So, to develop methods that are ideally, say, um, generated, keeping those You know, very unique clinical questions in mind, you know, for example, we developed a model, uh, for, uh, improved prior prioritization of patients on the liver transplant waitlist in order to, um, reduce the inequities on the waiting list.

Because in the end, you not only want to help the physician personalized care. Uh, for a given patient, but you also want, uh, the transplant recipients are transplant recipients to feel empowered in their care. And I think right now, what we have is when we see transplant recipients in the clinic. We can give them a general idea that we think they might be at a higher risk of this or a higher risk of that, but we, [00:34:00] um, don't have, you know, an exact estimation or, uh, an approximate estimation.

Like we can't provide a probability, and we can't also give them, say, a concrete list of modifiable and non modifiable risk factors that actually determine that probability of, uh, outcome. So if you could identify those predictors, which we can do actually with our algorithms, we can identify, so for this given individual, these are the risk factors.

These are the weights of their risk factors in providing that prediction and then, you know, you can, as the physician use that knowledge to help enhance and personalize the care of the patient in front of you. And all of that is basically, uh, it is based on whatever was learned [00:35:00] from. That original data set of over 200, 000 people and then further tested on the UHN data set of over 4, 000 liver transplant recipients.

So we use that information to then generate new predictions. And when we

Candice Coghlan: think about that as a, as a recipient, you know, getting generalized care. Versus getting very specific care that is also like what you said, um, when there are factors that could be modified. If I was told here are 4 things that you can change to have better outcomes with your transplant, you better believe I'm going home and making those changes tomorrow, right?

So that's amazing to get to hear that that would be such unique care for each person and that this technology would be able to do this for for us. Yeah.

Dr. Mamatha Bhat: Can I add on to that actually? So I think The other [00:36:00] thing I just wanted the other point I wanted to make so in transplant medicine. Um, a lot of what we do in practice is informed by observational or retrospective studies, not really informed by prospective randomized control trials.

Uh, I think, you know, moving forward, what we'd like to do is feed whatever data say regarding the interventions that have been made based on these algorithms, this algorithms prediction and the list of modifiable risk factors. We have made this these interventions are added these medications, and that data, like, is fed back into the algorithm, whatever outcomes happen over time, that data is also fed back into the algorithm.

So it continues to. Improve the the performance of that algorithm. So the algorithm learns from or it continues to learn from that additional data that keeps getting fed

Shilpa Raju: to it. I think to Martha's point to even some of these studies, all these things [00:37:00] have been done at a population level, but you're always going to have patients who are.

Don't fit that like that algorithm. I mean, what's been found in a study or the generalized results of a study. And so you do have always some of these outlier patients or even, you know, I've heard so many times from doctors have to have

like a side effect to something. It's like, well, it's not that like, it doesn't usually happen this way.

And then it happens. Or I'm, I'm sure I'm not the only one. But point being, there's always going to be people who don't fit that Quote unquote algorithm. And how do you account for some of that when you're treating or how can you be flexible to incorporate some of that? Like, yes, this is a standard regimen of care.

But if you know this patient is more sensitive to X, Y, Z for whatever reason, because we've observed these patterns over time, then how do we modify their care without having to go through the Do the thing and see the bad thing happen and then revisit [00:38:00] and you're absolutely

Dr. Mamatha Bhat: right about that. So for the immunosuppression, um, the level of immunosuppression that best balances the grafts well being versus the immunosuppressions side effects or systemic side effects.

That's the best balance for a given patient. And that balance is different for each individual person, uh, in order to understand that, say, in liver or in kidney, uh, you may have to perform a biopsy, you know, you often do actually to understand, you know, should I be giving this person more immunosuppression or less immunosuppression?

Because, for example, the liver enzymes don't tell us the full picture. Conversely, if it's someone who has a need for more immunosuppression, then you protect that graft. You optimize the survival of that graft for years to come by optimizing and personalizing that immunosuppression. [00:39:00]

Candice Coghlan: So thinking about, uh, and, and, you know, you don't have to answer this, but when we, when we talk about immunosuppressants, my brain always goes to tolerance and, you know, what the future looks like.

And Shilpa is, you know, probably laughing at me, but, um, you know, I, I always think, you know, how far out are we, um, in seeing that for, for certain people.

Dr. Mamatha Bhat: Well, in liver transplant recipients. Uh, it is quite possible to achieve tolerance in a subset of recidivism. So the liver is a very, you know, immunological, sorry, immunologically tolerant, uh, organ. And I think that's the beauty of the liver. In that over time, there is that potential to even say, wean people off of immunosuppression and reduce that risk of systemic or, you know,

[00:40:00] complications due to the anti rejection medications in the other organ groups and even in liver.

There have been say efforts to study a type of T cell called regulatory T cells. So those are cells that could. Induce tolerance, uh, and make the immune system react less to the organ, you know, recognizing it as more self as opposed to foreign. Uh, and I think there have been very interesting developments in this area.

So I think I'm, I'm hopeful that over time, uh, there will be at least that potential to. reduce immunosuppression, um, in kidney and lung and heart transplant recipients. Certainly, um, I think tolerance is a longer term objective in those organ groups because they certainly require [00:41:00] much more immunosuppression.

Now I'm not an immunologist, but I know that there's a lot of excitement around this kind of therapy. And, uh, I, I think, you know, we, we are going to see some interesting developments in the coming years, but I, I don't think tolerance is going to be achievable in the short term. It may be achievable in the long term, which with such therapies.

And I think, you know, it's, uh, That's very exciting because, uh, it would reduce that risk. Those all those risks that are associated with long term exposure.

Candice Coghlan: So I'm wondering personally, um, you know, you've, you've talked a bit about your research, um, but you know, you, you, you're very passionate about, um, you know, making this journey for, for us a better one and having long term, um, impacts on, on our lives.

Are there cases that touch you beyond this clinical space or that, you know, you might bring home personally because they've [00:42:00] been so impactful to you? And, you know, how do you deal with that?

Dr. Mamatha Bhat: Certainly, I think in, uh, liver transplant medicine, we are constantly, uh, seeing life and death in front of us, right?

So the liver, as I mentioned, there is no dialysis. Uh, for individuals with end stage liver disease. And so we try our best to keep people alive, uh, until they can get an organ offer. Or, uh, hopefully they get, uh, you know, they have, uh, a living donor who is able to donate to them. But there are unfortunately many people who don't make it on the wait list.

And I think... You know, those, especially, um, for me, what has struck me is especially if it's, uh, say a young mother, you know, so a mother of young children, particularly, and I've seen that, and that really has, you know, [00:43:00] uh, upset me as a mother myself, so I found that very upsetting. I think that really speaks to the need to improve, uh, organ donation, uh, improve access to living donor liver transplantation.

Thank you. And even beyond that, improve the equity of our liver transplant prioritization and allocation

Candice Coghlan: system. Um, so I'm wondering if there's anything else that you'd like to share either about upcoming innovation or anything that we haven't asked you about today.

Dr. Mamatha Bhat: I think, you know, I'm very excited about the future of AI and medicine in general.

And, uh, there's a lot of work happening in this space. Um, certainly in our day to day life, we've seen a lot of AI permeate our life in different respects. In healthcare, I think we've been a bit slower on the uptake, not just in the development, but also the deployment of algorithms. [00:44:00] And I think, you know, part of the reason is it's just very complex and you're talking about life and death and you want to say, be certain that an algorithm.

Will be able to improve upon what is currently existing. We don't want it to cause harm as opposed to, you know, benefit. And so one needs to establish that benefit and then establish that trust among physicians and patients. Now that involves education and also, you know, providing interpretability to these algorithms or interpretability to these models so that people understand why is it that it's predicting this.

Thanks. Um, increase risk or decrease risk. And I think that trust is essential to establish beyond the development of the algorithms that trust and then facilitating the deployment is really, uh, you know, very exciting to me that that we're able to do this at the edge [00:45:00] marrow transplant center that we will be, you know, leading the way in this space really worldwide in terms of actually practically deploying these algorithms.

Candice Coghlan: Thank you so much for, for joining us today on the podcast, Dr. Bott. We're so incredibly grateful. And, uh, like you said, the work that you're doing is exciting and it's fascinating. So we will definitely be, um, you

know, keeping in touch with, with, uh, this amazing research and, uh, we'll put links, um, in our show notes as well.

If people are interested in reading about the research that you're doing, but thank you so much for everything you do. We're very grateful.

Dr. Mamatha Bhat: Well, thank you so much for the invitation, Candice. And, uh, thanks Shilpa for, you know, providing those wonderful perspectives, uh, really, uh, appreciated your, your expert input as an epidemiologist, with lived, with lived experience.

Shilpa Raju: I was going to say, as an epidemiologist would live the [00:46:00] experience. Yeah. Yeah. No, it's been a great conversation. And yeah, I love hearing about this, um, work and I'm also so hopeful in the, in the same ways that I think you are, um, even as a patient.

Candice Coghlan: Yes. And thank you so much Shilpa for joining us today and sharing your journey and, and your experience.

It's so powerful. And, uh, we're very grateful for all of the work that you do as well with volunteer work and, and your day to day life. So thank you so much for joining us.

Shilpa Raju: Thanks for having me once again.

Candice Coghlan: Thank you so much. We hope you enjoyed this episode of the Living Transplant podcast. If you did, please leave us a review and share with your friends.

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