

CHRISTINE WU: But I feel like waitlist management's, of course, very important. Not everybody can find a donor, no matter how much we try to encourage them to and how much work they put into it. So we're going to talk about the patients who have to wait for their kidneys.

So what's the transplant list? The waitlist team, we're kind of like TSA at the airport. So United Network of Organ Sharing manages the list of all the people in the United States, and their job is to make sure that they get fair access to transplant. So for the majority of people, they just stand in line and wait for their kidney.

There is a pre-check line for certain patients. For example, pediatric patients get a little bit of an advantage and a shorter line, shorter wait. If patients are highly sensitized, meaning they're very difficult to match, they get points for that, and they get to move ahead in line as well. If a patient comes up with a perfect matched kidney, a six antigen match, they also get a little bit of advantage and a push forward to the front of the line. And then, of course, living donors, they don't even have to wait at all. It's like having your own personal jet at the airport.

So the University of Michigan stadium, one of the largest college stadiums, seats about 100,000 fans, and that's basically the number of patients, essentially, that are waiting for a transplant. About 60% are active on the waiting list, and only about 40%-- so 40% are inactive, meaning only about 60% of those 100,000, at any given time, are in the position and ready physically, socially, eligible for transplantation. About 3,000 patients are added every month, so that comes out to about one every 14 minutes. And then our transplant rate is about 18 per 100 people a year

So in our region-- you already heard from Dr. Tevar-- we have about 13,500 patients that are waiting. At UPMC, our waiting list-- of course, this is not a fixed number, because people are added and taken off every day-- we're roughly around 800 to 1,000 patients. The number of patients that were transplanted in 2017 was 215.

So of our 971 patients that we had on the list in 2016, 215 were transplanted. 80 deteriorated and were de-listed, meaning they became too sick and were no longer eligible for transplant. Then we had 50 patients who died on the list, and then a few transferred to other centers because they moved. We actually had two patients who recovered their kidney function and no longer needed transplant.

So date of listing I think still is a point of confusion for some people in the community. There was a rule change a couple years back to allow patients to get waiting time on the day they started dialysis. And so that can go retroactively. And that is to account for some areas and some places where there was less access to transplant.

And so, for example, minorities get referred to a lower rate for transplant. And so they weren't reaching transplant centers early enough to get on the list, so they were behind. They had been on dialysis for many years and just starting their waiting time. So now they get credit for all the time they've spent on dialysis.

There's still an advantage, though, to referring patients early. So if you're not yet on dialysis, you can also be on the transplant list and start accruing waiting time, as long as your kidney function or your GFR is less than 20 milliliters per minute. And so for those patients, if they're not referred at that point, they actually lose potential time that they could have accumulated on the waiting list.

So patients can start their waiting time either on the first day of regular dialysis, and they do get retroactive credit for this. Or they can get waiting time starting from the point where they're referred, complete their evaluation, and approved, as long as their GFR is less than 20. And they don't get retroactive credit for having lower kidney function.

The one thing we tell patients when they come to see us in evaluation clinic is don't assume that you're on a waiting list until you get the letter to say that you're approved, because some patients make the mistaken assumption that they've come, they've met with everybody, and they're listed that day. And that's not the case. So patients, again, who are not yet on dialysis, until they finish their evaluation and they're approved by the committee, their waiting time hasn't started yet.

So, again, I mentioned the status of the waiting list, active and inactive. 60% of patients are inactive on the waiting list. That means they're temporarily unavailable or unsuitable for transplant. Back in 2003, though, UNOS approved a policy for candidates that even though they're inactive, they still are in line. They're still accumulating and accruing waiting time. So there's no disadvantage to them in terms of their waiting time towards transplant. And active means that if a transplant comes up today and you're active on the list, you've been eligible to receive that kidney.

So the most common reasons for being inactive-- the vast majority is because this is incomplete workup. There are a lot of centers around the country. Once we think about all the time-- our California programs, UCSF, their waiting time's seven to 10 years.

So it doesn't make any sense when a patient's first referred to do their whole workup that day, because what does it matter? They're not going to get a transplant offer for seven, maybe 10 years. So they list patients all in the inactive status, and they don't try to even work them up until they get closer to the top of the list. We're still fortunate enough that our waiting times are short enough that, for us, it makes sense to evaluate and make sure our waitlist is a list of healthy, eligible patients for transplant.

Other reasons would be that insurance is an issue here. There are some patients that are just too sick. They've had recent surgeries, recovering from illnesses, and they're temporarily inactive. There are some patients who are too well.

So again, if somebody is referred for a transplant and they want to get on the waiting list and their GFR is 20 milliliters per minute, but they have a slowly progressive disease like polycystic kidney disease or hypertension, they have the advantage of getting on the list and starting to get that waiting time. But they don't need the transplant yet. And so we keep these patients inactive until their kidney function really progresses to the point where they would need a transplant. So that's what accounts for the "too well." And then there are patients who are either too heavy or too underweight, and then a very small sliver of other reasons.

So what's our responsibility as a transplant center? In the past, some governing bodies just let transplant centers manage any way we wanted to manage transplant list patients. Now there's a push to make sure that we're doing a better job of having an honest wait list. And they're trying to figure out ways to keep us accountable for our waitlist.

So they've come up with this composite pre-transplant metric, and it measures three things. First, they're looking at how many people die on our waitlists, so our waitlist mortality. They're looking at our transplant rate. Are we transplanting enough compared to other transplant centers?

And our acceptance rate. When we get offered an organ, are we using the organs that were offered appropriately? Are we turning down organs? This was prompted by some really high-profile cases of waitlist mismanagement. So, for example, there was a center with no full-time surgeon.

So if that surgeon happened to be on vacation, none of the patients were transplanted, or if he was busy or something. And so they had a very low rate of transplant and low rate of acceptance as well. And so you have to make sure that transplant centers are adequately staffed to maintain a fair transplant program for the patients that are listed there. And so those centers would not have been identified by the old measures, where we just looked at patient graft survival, because the patient graft survival seemed to be just as good as other transplant centers. And they were only picked up when you added these other factors.

For now, for kidneys, our regulators are only looking at-- whoops, sorry-- the last two, which is transplant rate and acceptance rate, because we don't have a lot of control over waitlist mortality rate. The general nephrologists out in the community manage these patients. We only see them maybe once a year for our older patients that we're worried about, or sometimes not until we see them again for transplant. So to keep our centers accountable for mortality doesn't seem quite fair.

And the other reason that they haven't added mortality onto our requirements is that there's no good measure of cardiovascular disease. And if you think about the number one reason why kidney patients pass away or die when they're on dialysis, it's cardiovascular. So if you can't measure that, how can you keep the centers accountable for that?

Unfortunately, insurance companies really don't understand that. And so they've picked up on this CPM, which was never intended to be used as a measure of quality in terms of deciding what transplant centers should be approved or not approved for different insurance coverages. So they're starting to use this data that we're collecting about waitlist mortality in terms of deciding which centers should be centers of excellence or not. So there are some unintended consequences of putting these metrics out there. For example, if you're accountable for waitlist mortality, maybe centers will be more, or less, likely to list high-risk patients and turn patients the way that they think might adversely affect their waitlist numbers.

So the CPM at UPMC, just to give you an idea, we're right on target. In terms of our death rate, it's actually a little bit less than what would be expected by our patient mix, just using the metrics that we have available now. Our transplant rate is exactly what it should be in terms of the number of patients on our list and how many are transplanted per year. And our overall acceptance ratio is actually a little bit higher, and we take and use more kidneys than the average transplant center.

So acceptance offers overall, UPMC-- this summer kind of surprised me, because I hadn't looked at it in a while. But nationwide, 1.5 million kidneys are offered up each year. The vast majority of them are not usable. So the acceptance rate is about 13,000. For UPMC, in one given year, we've had about 16,000 offers. And when you look through and sift through all of the data, 152 ended up being usable.

We also, nowadays, separate out kidneys in terms of quality, trying to use this KDPI scoring system. So it's a rough measure of how long we think the kidneys are going to last and how good the overall outcome should be. So with the scoring system, we're trying to understand which kidneys are good to use and which ones we should bypass, and which ones-- so they list them as low-risk, medium, high KDRI, and these very difficult to place kidneys that most centers would not use.

And as it turns out, we're on target for everything, except for the hardest to place kidneys. We don't use as many of those. And I think as a group, we've decided that sometimes these aren't good kidneys to use. I mean, you can get somebody off of dialysis, but are you really improving their quality of life if you get them off dialysis but there's still stage IV kidney disease because they've gotten a kidney that's sort of marginal? And so as a program, we don't tend to use quite as many of those.

So demographics. The age is getting older. About a quarter of transplant patients are over the age of 65. We don't have as many African-Americans in our demographic group just because we're in Western Pennsylvania. Our blood group distribution, 44% O, 40% A. We have very few AB. A lot of patients at UPMC have prior transplants. 38% are diabetic. And then we have 7% that are highly sensitized, very difficult to match patients.

Waiting times. So nationally, the median waiting time is 72 months. At UPMC, it's a little bit shorter, but much longer than when I first started doing this. So 14 years ago, our waiting times were about two years. We're now close to five years. It varies by your blood type. So As and ABs, for sure, have shorter waiting times than Bs and Os. And it also varies by how sensitized the patient is, how many blood transfusions they've had, how many pregnancies women have had in the past.

So for our highly sensitized patients, they get an advantage on the waiting list in terms of wait times. So when that rule change went into effect, we had a big bolus of transplants in that group. I think we're going to see these numbers tail off. We also have UPMC Hamot. If you look up their median waiting time now-- it's a small and new program-- but if you list the top 50 programs in terms of shortest waiting time, UPMC Hamot actually comes up on top nationwide. It's only a half a month right now. I'm sure that will change as the program grows.

So deaths on the waiting list-- overall mortality on the waiting list is about 5% per year. So that adds up to about 13 deaths every day for patients on the waiting list. So again, the importance of thinking about living donations so patients don't have to stay on this waiting list. The rate is even higher for diabetics. It's about 7% per year for a diabetic.

And it varies by age. If you're an older patient, you have a higher rate of dying while waiting for a kidney transplant. Actually, if you're over the age of 65, your chance, once you're listed, of dying is actually greater than your chance of being transplanted, even if we successfully get you on the list.

So from last year, we had about a 5% rate of mortality on our waitlists. And if you're inactive as a patient as opposed to active, it usually means you have a lot of other medical issues going on, and that's why we have you inactive on the list. So those patients actually had double the rate of death as our active patients on the list.

So how do patients maintain an active status? They have to stay current with their age-appropriate cancer screening. For patients over the age of 65, and then also for select patients that we identified when we first list them, we will see them yearly or maybe even more than yearly while they're on the waiting list, just to make sure they're still appropriate for transplant.

If we have some questions-- for example, some of our older patients, when they show up on the first day, we're not sure, maybe there are some early signs of dementia, we'll see them again. If there's a little bit of a functional issue-- they're walking with a cane, a little unsteady-- we want to make sure they're not deteriorating, that they're actually improving their physical condition or at least staying stable if we're going to keep them on the waiting list. We also rely a lot of on our social workers to identify any social issues that come up with patients on our list.

Sometimes they identify an elderly spouse as their primary caregiver. Something happens to the spouse. Caregiver expectations will change while the patients are waiting. And some high-risk patients, non-compliant ones, ones that don't show up to dialysis regularly in the past, or maybe had a past organ transplant that didn't last because they stopped taking their medications, we put them through what we call our social work hoops. We may make them come every couple of months to meet with our social workers, behavioral health therapists and team to make sure that they've changed their ways and they understand what they're doing. We will also keep in regular contact with dialysis units to make sure they're compliant with their dialysis treatments and taking their medications.

Cardiac testing is something we've changed a lot, I think, since I started doing this, at least, 10 years ago. In the past, we used to just mandate, everybody gets a stress and echo every year while they're on the waiting list, whether they're high risk or whether they're low risk. We're trying to be a little bit more rational in our approach to cardiac testing. There's very little data, if you go out and in the literature to look, at what we should be doing.

So we tried to, as a group, come up with what we think makes sense. So the frequency will depend a lot on the age of the patient and what their prior cardiac testing has shown. Obesity, we have a-- it's kind of a soft cutoff, I'll say, of 40. If they're over 40 and we're not quite sure, we just ask Dr. Tevar to see them and ask him if he would transplant that patient. And he either gives it a thumbs up or thumbs down. We have exceptions for muscle mass. Again, these former football players where the BMI doesn't reflect obesity, their BMIs may be much higher and still be reasonable for transplant.

So why do we make a-- our focus on BMI is not just us, but nationwide. If a patient has a BMI of over 45, their chance of actually getting to an active status on transplant is less than one in four. So we offer nutrition support. We also try to encourage them to talk to their family doctors, as well as consider signing up with UPMC weight loss or their local weight loss centers to get counseling, maybe even surgical intervention for weight prior to transplant.

Common reasons for removal-- newer progressive medical contraindications. We rely a lot on patients and dialysis units to help us with this. If they're in the UPMC system, we oftentimes will get alerts when our waitlisted patients are in with something new, and we'll find the information sometimes even before patients will tell us. And some patients are scared to tell us because they don't want to be de-listed.

But it's very important to know that, because if we find out that they have this condition when they come in for their transplant-- even though they've taken the two hour drive to come to Pittsburgh, if we discover it on the day that they're here-- we turn them away from transplant. They don't get their organ. And so not only did they waste their trip, but we potentially wasted important time trying to get the next patient in for transplant to use that organ.

So progression of heart disease, new cancer diagnosis, loss of function, progress of dementia are reasons that we've removed patients. Sometimes patients transfer to a different center because they've moved out of town, or they've retired. They're relocating. Insurance changes. Highmark is the big question that comes up, I think, every year.

And then patients that are unable to be contacted. So we've tried calling a couple of times. We've tried calling the dialysis unit, asking if they're interested or not interested. They don't call us back. That's a red flag to us. If we can't get them to respond to us about getting an organ, how likely are we going to get them to comply with their lab work after transplant?

Loss of caregiver support and aging out. So I'm going to spend a little bit of time on this, because that's a common question. Am I too old for transplant? If I'm 70 years old and I don't have a donor at the time I'm listed, what's the chance that I'll get a transplant? Will I age out of the system? And the answer is actually maybe.

So here's this quote. Just highlights the problem with statistics. If you live to be 100, you've got it made. Very few people die past that age. And the life expectancy is definitely increasing worldwide.

So we're getting more and more patients that are referred to us that are older. Not only is life expectancy increasing, but also active life expectancy. So the 70-year-old today doesn't look like 70-year-olds did 20 or so years ago. People say 70's the new 50-- maybe.

So we went back and looked at our own data on the waiting list and transplants. What happens to people who are older, and how do they do on transplant? Well, turns out we did a pretty good job of picking our older patients that we decided to transplant. In fact, if you look at how they did, they actually did the same or even better than our younger patients. So there isn't an absolute age limit if you select patients appropriately for transplant.

The problem, though, is while patients still-- their basal function doesn't change a whole lot with time, their reserve really decreases. And so when we do a test, a one-time test, on a patient, a stress test, we're kind of testing their basal function. We're not really testing what their reserve is. And when you look at our current way of following patients on the waiting lists and doing our evaluation by single-organ systems-- chest X-ray for the lung, a stress test for the heart, colonoscopy for a cancer screening-- we miss a lot, because we don't take into account the whole person or whole patient.

So the current method of doing things, people have estimated that about a third of the patients that we approve and list for transplant actually have a three-year mortality of over 50%. So we're not so great at predicting who's going to live. There are some measures that take into account probably more than just a single organ function, and gait speed tends to be a nice marker that wraps a lot of things together-- neurological function to keep balance, muscle function for mobility.

And so we've added this as one of our waitlist test when patients come to see us. We'll measure how fast they walk, how quickly they can get up and down out of a chair. And this is the same picture that Dr. Tevar showed. We have to understand that there is sort of a diminishing return as people age in terms of getting a transplant. So when does it become not such a great idea to transplant patients?

There's also the cost idea, too. Cost per quality adjusted life year that you're gaining-- when you're young, it makes a lot of sense, because these patients are going to live 20, 30 more years. . So for every dollar that you spend and transplant, you're going to recoup that in terms of quality years back.

If you have an 80-year-old on your list and their waiting time is at least four years-- I'm sorry this is cut off-- but the estimated cost per quality life year that you're giving them is about \$14 and 1/2 million. And so when you talk about how strapped our health care system is and how are we going to limit costs, we do have to be a little bit reasonable and rational in terms of how we decide who should and shouldn't be transplanted.

So what have we done at UPMC on our waitlist? Well, we try to customize the frequency of our surveillance testing, and especially our cardiac testing. Definitely encourage living donor transplant. We have those workshops to encourage patients to develop contacts through social media-- really helpful, I think, for older patients. I mean, my parents still don't understand how to text, even though my kids have been trying to explain that for the last year.

We have expanded surveillance. So in the past, we would see patients at waitlist and then not see them again until transplant. Sometimes we were sort of shocked when we called them in, and this is the patient that we were supposed to transplant that night. It's much harder to have those conversations about a patient not being transport-worthy or not being transplant-ready when the organ's there, and there's a time crunch, and the patient's made that four-hour drive or two-hour drive with all of their family, and they're waiting and expecting an organ transplant than it is to do it on a regular basis in the clinic, face to face, when you have more time to have that discussion.

But we mandate waitlist appointments every year for patients over the age of 65. And then for other considerations, like frailty or cognitive decline, shaky social support, we'll see them more often. And then because patients can still have waiting time retroactively to the date that they started on dialysis, we've sort of moved to de-listing rather than inactivating patients who we think are downhill or a downward trajectory. And we want to have early discussions.

So if a person is declining, it doesn't make sense or it's not fair to them to keep them in that line and to have them do this yearly testing with hope of getting a transplant if we really don't think that that's possible. And so we've moved to having these early discussions with patients about the possibility that they might be removed from the transplant list. Trying to limit the number of patients that we list above the age of between 70 and 75, especially if they have co-morbid conditions or if they don't have any possibility of living donors.

And now moving, I guess-- we've always understood, but now we think about this more, about the fact that the majority of elderly patients, they value quality of life probably more than life expectancy. So that's part of our discussion with patients, to really make sure that they understand that transplant for them-- for a patient over the age of 70-- we're not really promising longer life. What we're trying to do is make sure that transplant for that individual is going to improve their quality of life.

One thing that Dr. McCauley, before he left, used to always talk about to fellows was that sometimes our older patients, especially the ones who live alone, dialysis is their social network. It's basically their second family. So if you take that away from them with a transplant, they don't have dialysis anymore.

And to us it might seem great, but they've lost-- we had one patient, actually, who used to run dialysis bingo, and she was the queen of the dialysis bingo. And she had a successful transplant, but I don't think she had the same-- in our minds, it was a success. But for her, she asked a few of us if she could go back to dialysis. And so those are things that we have to think about.

We do have weekly waitlist meetings-- and this is something that's new since Dr. Tevar came-- which I think has been helpful in terms of making sure that our waitlist, for the most part, is healthy, that our surgeons aren't surprised in the middle of the night when they call that patient in with some positive stress test that was buried in some outside folder that we never got to. So we do have-- Dr. [INAUDIBLE] and I review stacks of waitlist testing every week, go through all of the stress tests and CTs and everything that comes through from outside hospitals on all of our waitlisted patients.

So a couple of things that we've been able to do by following these waitlist patients a little more carefully is to look back at our data. So, for example, left heart cath is something that comes up. A lot of people don't like. It's sort of a more invasive test than stress test. But we know in the kidney community that stress tests are terrible for picking up heart disease in our patients, because our pretests probably-- the majority of our patients have heart disease. So the false negative, or the chance a negative stress test will miss heart disease, is pretty high in our patients.

So about 15 years ago, we said that any patients who had diabetes for over 20 years on dialysis should get a left heart cath, regardless of whether their stress test was negative or positive. So we took a look back, and the cardiologists gave us a lot of pushback because they said, you're not following current guidelines in terms of how you're stress testing patients. If they have a negative stress test, there's no reason for a left heart cath.

And we kept saying to them, that doesn't fit with what we're seeing. We have a lot of patients who have negative stress tests. They have heart attacks after their transplant. We don't want that to happen. So we kept going with our left heart cath, and then we looked back.

So we had at least 80 patients, mean age of 56. 2/3 of them were on dialysis. They all had diabetes for 20 years, all with a negative stress test, and all reported normal function, no symptoms at all, no chest pain. But we said, we don't care what your cardiologist says. We still want a left heart cath anyways. And if your cardiologist won't do it, we'll either call them or set you up with a UPMC cardiologist.

And what we found was that at least 10% of them had left main or proximal LAD lesions that were over 70%, so a widowmaker in the works. And almost 19% of them ended up having some intervention done, whether it was stent placement. 6% had a bypass surgery.

So we think that this is actually something that was useful that we continue to do. But then we also were able to look and see which of these patients, which of these 80, fell into the group that actually needed to have something done. So it turns out that if you have a history of stroke or peripheral vascular disease, prior history of ever smoking, or poor control of your diabetes-- any one of those three-- you fell into the category that ended up needing intervention. If you didn't have any of those three, very unlikely that you would need an intervention. So I think we can even refine our testing strategy a little bit more by looking back at what we've already done.

How do you shorten your waiting time on the waiting list? How do you get it to be less than five years? So again, you saw this map. We're in region two here, and the average waiting time in our region's about five to six years or four to six years.

There are some companies out there, entrepreneurial-- there's a guy at CMU who came up with this company called OrganJet. So if you have \$15,000 a year, I think it is, base to start with, they'll guarantee that they'll put you on a jet and fly you to any transplant center in the country within a moment's notice, and they'll get you to your transplant. So then you can multi-list.

You can look up on this database, Transplant Interface, and you can comparison shop. It's like those online car shopping things where you can load up all different places that you might want to visit or might want to get your transplant and comparison shop transplant centers. So that's a possibility-- not financially feasible for the vast majority of our patients. So living donors, again-- living donor, living donor, living donor. It's the only really realistic way of shortening time on the waiting list.