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## Bridging The Cardiology Gap: Care Priorities for Adults With Congenital Heart Disease

Narrator:

Welcome to Medical Breakthroughs from Penn Medicine: Advancing Medicine Through Precision Diagnostics and Novel Therapy.

Dr. Caudle:

This is ReachMD, and I am your host, Dr. Jennifer Caudle, and joining me today is Dr. Yuli Kim, Medical Director at the Philadelphia Adult Congenital Heart Disease Center and Assistant Professor of Medicine in Pediatrics at the University of Pennsylvania and the Children's Hospital of Philadelphia. We'll be discussing acute congenital heart disease, which is a relatively unknown subspecialty.

Dr. Kim, welcome to the program.

Dr. Kim:

Thanks for having me, Dr. Caudle.

Dr. Caudle:

So, let's start out. What do cardiologists need to know about the field of adult congenital heart disease?

Dr. Kim:

You know, the field of adult congenital heart disease is a relatively new specialty, so one thing that I think practitioners should be aware of is the fact that it actually exists. It was not formally recognized until 1990 by the Bethesda Conference, and the reason why it's a relatively new subspecialty is because babies who were born with congenital heart disease unfortunately in the past did not survive infancy or even childhood often times. With the advances in surgery and medicine and ICU care, we now expect that over 95% of babies born with congenital heart disease survive to adulthood, which is why we have this new subspecialty that really wasn't around a few decades ago. So, I think knowing about the subspecialty is the first step.

Dr. Caudle:

Can you talk about who should be cared for in an adult congenital heart disease center, and really, what sort of patients do you see?

Dr. Kim:

Now, we see patients who have congenital heart disease of all different types of complexity, so we see patients with relatively simple congenital heart lesions such as atrial septal defects, ventricular septal defects, pulmonary valvar stenosis, but we also see patients with very complex congenital heart disease. These are patients who have hypoplastic left heart syndrome, for example, or transposition of the great vessels. These patients were the ones who traditionally didn't survive infancy way back when in the day when cardiac surgery was not readily available to fix these lesions, and so we see patients of all different types.

The patients that we really should be seeing on a more regular basis are those who are considered to have moderate to complex disease. So, even though we do see patients with relatively simple disease, we believe as a community that adult congenital heart specialists should be routinely taking care of patients with moderate to complex disease, and this includes lesions such as Tetralogy of Fallot, Ebstein's anomaly, for example, single ventricular disease, as I mentioned, and transposition of the great vessels. These are the ones that should be followed on a regular basis. In the past, these patients, when they had their corrective surgery, were told that they could go and live a normal life because they were "fixed," but we know now that that's not the case and that these patients require lifelong congenital care, hopefully in a center that specializes in adult congenital heart disease.

Dr. Caudle:

Can you talk a little bit about what some of the innovations are in the adult congenital heart disease realm?

Dr. Kim:

So, most of our patients, not all of them, but most of them have undergone some type of corrective or palliative heart surgery in childhood. There are, of course, adults who pop up into our clinics who were recently diagnosed with congenital heart disease, and these are usually of milder forms. The innovations that are arising or developing in our subspecialty really revolve around devices such as percutaneous valves. So people may know about transcatheter aortic valve replacement. We in the congenital field are now developing transcatheter pulmonary valve replacement, which is on the other side of the heart. This is, obviously, not as common as transcatheter aortic valve replacement, but this is a really new and growing aspect of our field that's very exciting for me because it does save our patients who often have had open heart surgery, another open heart surgery. That's one example of a really fascinating and really promising innovation that's going on in our field.

Dr. Caudle:

If you're just tuning in, you are listening to Medical Breakthroughs from Penn Medicine on ReachMD. I am your host, Dr. Jennifer Caudle, and with me is Dr. Yuli Kim, Medical Director at the Philadelphia Adult Congenital Heart Center at Penn Medicine and the Children's Hospital of Philadelphia.

So, what are some of the more common conditions that you treat?

Dr. Kim:

I think that the most common conditions that we treat in a specialty center are complex disease lesions such as Tetralogy of Fallot, which is, I would say, probably the most common, the most common lesion that we treat. Now, this is a condition that was initially palliated in the 1950s with shunt surgeries, and as I mentioned earlier, there have been advances in the field of cardiac surgery such that now these patients are growing and thriving well into adulthood and beyond, and this probably comprises the majority of the complex lesions that we see. And, of course, there are other patients who have less complicated congenital heart disease lesions such as coarctation of the aorta, bicuspid aortic valve, congenital valvar abnormalities. These are the types of patients that we see in our program.

The other condition that we treat is pregnancy. So, one really gratifying aspect of our subspecialty is being able to counsel women who have congenital heart disease, and these are patients who may have been told in the past that they are not able to have children or it's not safe for them to have children. We know now that many of these patients can safely have children and go through pregnancy as long as they're followed in a high-risk adult congenital heart center that partners within the maternal-fetal medicine specialty clinic. And this is a patient population that we specialize in as adult congenital cardiologists. It's very gratifying for the patients or families to know that they can have a safe pregnancy as long as they are supervised properly.

Dr. Caudle:

Absolutely. My next question is something that I think a number of our listeners are probably wondering about. Let's talk a little bit about your particular background. Are you a pediatric or adult cardiologist, and what is the training background of those in your program?

Dr. Kim:

The field of adult congenital heart disease, as I mentioned earlier, is relatively new, so most of the people who take care of adults with congenital heart disease are pediatric cardiologists. Now, the field is changing, and there is more of a push towards formal training in adult congenital heart disease. So, my personal background is one of internal medicine, so after residency in internal medicine, I went on and did a fellowship in adult cardiovascular disease, and then I did a subspecialty training fellowship for two years in adult congenital heart disease. And this is where our field is going. We have recently administered the first set of boards for the adult congenital heart disease subspecialty, which is administered by the ABIM, American Board of Internal Medicine, and that was given last year for the first time, so now we can sit for our boards. And as I mentioned earlier, the push is really for subspecialty training.

Now, you don't have to go through internal medicine, so another route that you can go through is through the pediatric route, so you can do a general residency in pediatrics followed by training in pediatric cardiology and then again another two-year subspecialty fellowship in adult congenital heart disease. My partners have a mixture of these backgrounds, and for example, one of my partners has a residency background in med-peds, so she's done both, and she also did both adult and pediatric cardiology in addition to her adult and general heart disease fellowship. So, I think that you can come from both aspects, and the field is open to both of these avenues in working towards board certification in the subspecialty.

Dr. Caudle:

How do you think the field will evolve over time and in the future?

Dr. Kim:

That's a really great question, and I think a lot of people are trying to look forward and see how this is going to play out because it's a relatively new subspecialty. I think it's all going to come down to making sure that people are board certified, number one. I think that there's a dire workforce shortage in terms of adult congenital heart disease providers, and I think that it's incumbent upon us to train the next generation of adults and general heart disease providers and provide training opportunities through the formal fellowships that are being recommended. I also think that the care of adult congenital heart disease is going to go through a real big evolution in terms of standardization. So, currently, the field is undergoing an accreditation process, which is sponsored by the Adult Congenital Heart Association. Now, this is the accreditation body that is going to be evaluating and assessing adult congenital heart disease centers across the United States and giving the accreditation stamp that this is an official adult congenital heart disease center. So we are really working towards standardization of training as well as standardization of care such that we can provide the highest quality care for our patients.

Dr. Caudle:

Well, before we close, Dr. Kim, I just wanted to ask you, is there anything else that you would like to add today?

Dr. Kim:

There is one thing that I probably should mention, which is another aspect of the care for this patient population. We do believe that there are patients out there that are what we call lost to care, and I had alluded to this earlier, but there was a point in time when providers were told that patients didn't need to come back, that they were "fixed," and this has actually resulted in a lost patient population of adults with congenital heart disease who are out there who don't even realize that they need to be plugged into adult congenital heart disease care. I mean, there's research out there showing that these patients are still plugged in with their primary care physicians, and so one thing that I would really like to make sure that our listeners understand is that if you have a patient with a congenital heart disease, whether it's simple, moderate or complex in severity, please make sure that they get to see an adult congenital heart disease provider, because it's probable or possible that these patients don't even realize that they need to be seen by a specialist.

We know that patients who are lost to care from a congenital center actually return back to care sometimes with acute illness and they require interventions, often times surgeries or catheterizations, and we do believe it's best for them to be retained in care. So one of the things that we're working towards is trying to set up transition programs across the United States such that these patients don't get lost, especially in that vulnerable period when they transition from pediatric to adult care. So, I think these are two patient populations that get lost, the older ones who get told not to come back because they're fixed, and then the patient population that's at a vulnerable age, so this is the 18- to 21-year-old age bracket where they're just starting to become independent; they're going off to school; they feel invincible; they feel good; they feel healthy; they don't need to go to a doctor; and then they don't go back. I think it's really important that providers, if you see these patients, to ensure that they get back into congenital care, because it's really going to be the best for them in the long-term.

Dr. Caudle:

I think that's an excellent point. I think it's a great reminder and a lot of good education for our listeners. Dr. Kim, thank you so much for joining us today to talk about adult congenital heart disease.

Dr. Kim:

Thank you so much for having me.

Dr. Caudle:

I am your host, Dr. Jennifer Caudle, and thank you for listening.

Narrator:

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