Importance of Adult Congenital Heart Patients Getting Multidisciplinary Care

Convention Connection: AHA Scientific Sessions

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Andrew Schorr:

Andrew Schorr on location in Chicago at the American Heart Association Scientific Sessions. This is where heart specialists from around the world are here to discuss the latest heart research. One area of concern is are adults, who had heart problems as children, getting the best care, the care they need to live a long full life. An expert in that and who is presenting research here, is Dr. Yuli Kim. She’s with the University of Pennsylvania, Penn Medicine.

Dr. Kim:

So I think it’s really important to understand the landscape of the problem here. The face of congenital heart disease has changed tremendously over the past few decades. For the very first time in history, we have more adults with congenital heart disease than children. So the estimates are that there are approximately 1.3 million adults with congenital heart disease living in the United States. And this is mostly because of advances in medical therapy and surgical therapies such that babies that are born with congenital heart disease, over 90 percent of them are expected to reach age 18. So this is a growing population.

Andrew Schorr:

That’s great news, but what’s the significance for them as adults? What’s the concern? Were they cured as children?

Dr. Kim:

No, and I think that’s a really important point to make here is that a lot of these babies or children who repaired in childhood, were often told that they were good to go, that they’re fixed, see you later, have a nice life. And that they were told to lead normal, healthy lives, and many of them do lead normal, healthy lives, but there’s a subset of these adults that are missing to care. So they’re lost to care, we don’t know where they are, and they pop up later in life with complications that we know of, such as heart failure and arrhythmias and perhaps even sudden death.

So the message we try to get out patients is that if you have congenital heart disease that was repaired in childhood, you’re not fixed. You are encouraged to find a subspecialist in adult congenital cardiology because we know that these patients have lifelong health concerns that should be followed by a specialist.
Andrew Schorr:
But millions of Americans develop heart disease. All these issues as we age, why would it be different for someone who had heart problems as a child?

Dr. Kim:
That’s a good question. A lot of times the babies or the children who are repaired in infancy or childhood, surgically have sequela of congenital heart disease that are very different than the adult acquired disorders that we think about, such as atherosclerosis, hardening of the arteries, strokes, diabetes. They have the sequela of the congenital heart disease that we follow, but then they also have these adult problems that everyone gets – not everyone, but that people get when they get older. So it’s sort of the conflation of the two different long-term outcomes, congenital heart disease and acquired heart disease that make this subspecialty very different.

Andrew Schorr:
Are you saying that if someone had childhood heart problems, was treated for that, and then later in life, maybe there’s another shoe that drops, there are issues from that, or they just develop heart issues as well do – many of us do when we age, that if they go to the typical adult cardiologist, they may not have the familiarity with what that patient needs?

Dr. Kim:
That’s exactly right. I think that we as a medical community, are faced with this growing population, more hospitalizations, more resource utilization, increased primary care visits, but we’re not very well equipped to take care of the specialized health needs of this population. And for example, the adult cardiologist out there may not have familiarity with congenital heart disease because as I said before, this is a whole new paradigm. We’re actually seeing these children now surviving to adulthood with congenital heart disease and being presented to the adult population clinics for the very first time.

Andrew Schorr:
So what is the message for someone watching or a parent if someone has been treated for a heart problem as a child, as an infant, as a teenage, what sort of specialist should they be seeing? What sort of center should they be going to?

Dr. Kim:
Yeah, that’s a really good question. So the message to the patients and also parents of patients are that we as the adult congenital heart disease community recommend that adults with congenital heart disease be seen by an adult congenital heart disease specialty center. There are approximately 70 such centers in North America at the current time. These are self-identified centers that are listed on the Adult Congenital Heart Association Website. And these are the centers that as a community, we are supportive of. Because it supports regionalization of care.

And what I mean by regionalization of care, it means that these are centers that have adult cardiologists, pediatric cardiologists that are familiar with congenital heart disease
along with a whole host of other subspecialists who are familiar with adults with congenital heart disease. Those are cardiac surgeons, obstetricians who are used to helping women with congenital heart disease delivery babies safely, nephrologists, hepatologists, anesthesiologists, perfusionists, nursing, mid-levels.

I mean, this is a whole team of people that are familiar with the care of congenital heart disease. And we as a community recommend that everyone with adult congenital heart disease be seen at least once by somebody in the center. Those with moderate and complex congenital heart disease, we encourage them to be seen much more frequently because the expertise of care may not be so widespread as we’d like.

Andrew Schorr:
And the bottom line from your research is going to a center such as that rather than being lost to care, as you described, could make a huge difference in your health?

Dr. Kim:
It could. I want to point out the fact that the research that I was looking at, that I’ll be presenting during these AHA sessions are actually focused on the pediatric hospital setting alone so one big hot area of debate in our subspecialty is where should these patients be seen? Should they be seen at the adult hospital? Should they be seen at the pediatric hospital? And I’m focusing specifically on the pediatric hospital and the adults who actually undergo surgery in that setting. The results of the research suggest that if you’re an adult with congenital heart disease undergoing congenital heart surgery in a pediatric hospital, the pediatric hospitals that have high volume adult congenital heart surgery, have lower likelihood of death for those patients.

So yes, for that specific subset of patients, we do think that our research supports regionalization of care, going to a high volume adult congenital heart center in a pediatric hospital is good for the patient. There are approximately 70 such specialty centers in the United States. And the center that I’m the director for, is a joint program between University of Pennsylvania, Penn Medicine and Children’s Hospital of Philadelphia, again, underscoring the need for a cooperative collaborative model of care between a children’s hospital and an adult hospital.

Andrew Schorr:
And are hope is with that sort of care, someone who had a heart problem as a child, can live a long, full life.

Dr. Kim:
That’s right, that’s right.

Andrew Schorr:
And it makes a difference.

Dr. Kim:
It does.
Andrew Schorr:
And of course, the hope is adults who were treated for heart issues as children, when they get quality care, will lead a long, full life. On location in Chicago, I’m Andrew Schorr.

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