

Mayo Clinic Podcast - Dr. David Majdalany - YouTube Audio - ...

📅 Thu, 3/18 4:37PM 🕒 28:04

SUMMARY KEYWORDS

patients, congenital heart disease, cardiologist, pregnancy, disease, provider, adult, care, heart, adult congenital heart, mayo clinic, issues, pediatric, heart disease, baby, intervention, defects, depending, cardiac, cyanotic

SPEAKERS

Dr. Halena Gazelka, Dr. David Majdalany, Narrator

-
- N** Narrator 00:02
Coming up on Mayo Clinic Q&A:
 - D** Dr. David Majdalany 00:04
Part of the challenge is a lot of these defects may be silent when they're born, and may come to surface as they get older. Even for our female patients, you know, pregnancy may be the first test where we can find that there may be an underlying problem that was never really discovered.
 - N** Narrator 00:20
That problem is congenital heart disease, a condition of the heart structure. One in 100 babies are born with some sort of issue, but advances in diagnosis and treatment can allow them to live long and productive lives.
 - D** Dr. David Majdalany 00:33
These patients would certainly require long term surveillance to make sure those mild

abnormalities are not causing any further stress in their heart as they're growing older.

D Dr. Halena Gazelka 00:43

Welcome, everyone to Mayo Clinic Q&A. I'm Dr. Halena Gazelka. Congenital heart disease is one or more structural problems with the heart that have existed since birth. While some congenital heart defects cause no problems at all, others can cause life threatening complications. Advances in the diagnosis and treatment in babies are now allowing individuals with congenital heart disease to live well into adulthood. Sometimes, the signs and symptoms of congenital heart disease are not even evident until people are adults. Here to discuss adult congenital heart disease is Dr. David Majdalany, a cardiologist at Mayo Clinic in Arizona. Thanks for joining us today.

D Dr. David Majdalany 01:25

Thank you very much Halena. I'm honored to be part of this program.

D Dr. Halena Gazelka 01:28

Well, you know, I always say that I love to learn something. And I know I definitely can learn something from you today about congenital heart disease in adults.

D Dr. David Majdalany 01:37

Well, I'm sure we are learning each from each other in this, you know, in the advancing medical field, we teach and learn from each other. And our patients teach us as well.

D Dr. Halena Gazelka 01:48

That's right. So, David, my first question for you today is how common is adult congenital heart disease?

D Dr. David Majdalany 01:55

That's a good question. I mean, adult congenital heart disease probably encompasses about, you know, about close to 1% of all births. And, you know, as you mentioned, as the advancements in medicine, in diagnosis and intervention, has been prospering over the last few decades. You know, we have a lot of these patients are living into adulthood, and there's even more adult patients with congenital heart disease now than there are pediatric patients with adult congenital heart disease. So, it certainly is a growing

population.

D

Dr. Halena Gazelka 02:29

Wow, and you know, that's really interesting, because 1% may not sound like much, but when you think about all the births, one in 100, babies having some sort of difficulty like this is really kind of significant.

D

Dr. David Majdalany 02:40

It certainly is significant. I mean, you know, part of the challenge is a lot of these defects may be silent, when they're born and may, you know, come to surface as they grow, you know, as they get older. Even for our female patients, you know, pregnancy may be the first test where we can find that there may be an underlying problem that was never really discovered before pregnancy.

D

Dr. Halena Gazelka 03:03

David, in my years before only doing pain medicine, I'm of course an anesthesiologist, and I recall that many of the patients that I would take care of in the operating room had pediatric congenital heart specialists even far into adulthood. So, adult congenital heart as a specialty is a little bit newer, I think. That's right. I mean, you know, the training now encompasses two years after you're done with your general cardiology fellowship. There are some real pathways you can get, you know, appropriately trained, and then be eligible to pass the board for adult congenital heart disease. So, we do have a lot of providers from the adult side that train, and then some, also providers from the pediatric side that been in adult congenital heart disease. And I think we both help the patient overall. And then we bring different perspectives into their care, where you know, a lot of these patients had the rapport with the pediatric cardiologist, they entrusted their life in the decision making with him, and then, you know, as they grow older, they do start experiencing, you know, the normal problems that patients, you know, get with age, you know, high blood pressure, diabetes, coronary artery disease. So, these are the things that the perspective of the adult cardiologist may kind of be a little bit more aware of in terms of testing, preventing and managing those issues. But, I think you know, patients can be managed with both providers, and sometimes it's a good idea for both of these providers to collaborate in the care of those patients. That is really interesting. David, I had never before really thought about. I always thought about the heart disease as being the structural defect, but obviously, as people age and people will survive and have surgeries for these defects, then they go on to be adults with the other problems that the rest of us face. That's so true. I mean, again, I've taken care of patients with, you know, pregnant

patients. And you do see sometimes manifestation of adult heart disease in addition to the congenital heart disease that we have to keep in our mind as they progress through different stages of pregnancy and delivery and even consider future pregnancies. So, it is true. I mean, a lot of our female patients are delaying pregnancy into their third or fourth decade, and then they start encountering some aspects of the, you know, heart disease that we see traditionally in adults. That's really interesting. I want to start by asking you about congenital heart defects. Does almost everyone or everyone who has a congenital heart defect, end up needing some sort of a surgery to fix it, and does surgery fix all of these?

D

Dr. David Majdalany 05:46

Well, I mean, the adult congenital disease, it's kind of a spectrum of issues. There are certainly some abnormalities that may be considered simple congenital heart disease, such as atrial septal defects, you know, patent ductus arteriosus, maybe mild valvular narrowing or leaking, ventricular septal defects. So, I mean, a lot of these simple abnormalities, you know, depending how they're impacting the heart, may or may not require interventions. But there are a lot of these patients, which certainly would require long term surveillance to make sure those mild abnormalities are not causing any further stress in their heart as they're growing older. Now, there are certainly more complex congenital heart diseases, you know, what we call the cyanotic congenital heart disease where patients have low oxygen levels in their blood. Those can include things like Tetralogy of Fallot, transposition of the great vessels, you know, patients born with, you know, what we call single ventricle physiology, those types of patients, you know, rarely surviving adults without some sort of intervention, or actually, many of them require multiple interventions through their life. And then we really need lifelong follow up. I mean, I do encourage all our congenital patients to at least have some relationship with a cardiologist that's aware of their congenital heart disease, that are aware of the long-term effects of that congenital heart disease on their life, whether or not they have or have not required the intervention. And especially for our female patients that are entertaining pregnancy, if that's some element of congenital heart disease, they should certainly seek an updated cardiovascular visit, you know, kind of get a pre-pregnancy counseling to make sure they're able to sustain the pregnancy safely and have the best outcome for mom and baby.

D

Dr. Halena Gazelka 07:32

I want to get back in a moment to women who want to become pregnant who have heart disease. But I wanted to ask you first about a term you use the word cyanotic, and I'm wondering, does that refer to what I learned in medical school as blue babies?

D

Dr. David Majdalany 07:46

Yes, you know, it is, you know, cyanosis doesn't, you know, reflect what are called blue baby low oxygen levels in the body. They may be either due to over circulation of blood to the lungs, or meaning that we're not able to send the blood to the lungs to get oxygenated. So yes, your term cyanotic in simple words, means that the patient has, you know, sometimes they have blue lips, blue hands, they may have some unusual curvature to their fingernails, have had long, you know, effects of these low oxygen levels on their body.

D

Dr. Halena Gazelka 08:21


Which sounds like it would be indicative of a fairly serious defect, as he said, that would require some kind of intervention. Right. I mean, there are certain types. Yes, I mean, a lot of these patients with cyanotic, congenital heart disease, you know, they usually get picked up early in childhood soon after birth. And, you know, they can know what the issue is, like, you know, diagnose it and see what's the best way to help the patient so that, you know, we do want to minimize the amount of months and years as much as possible patients or babies are kind of living on low oxygen levels, because it's kind of the fuel for the body. And if you don't have fuel, you don't really go very far, or as far as you'd like to go. David, how do you make sure that these pediatric patients don't fall through the cracks, so to speak, when they reach adulthood and they continue to receive regular cardiac care?


D

Dr. David Majdalany 09:12

I mean, that's a common issue that we encounter in our patients. You know, many patients have been born with a congenital heart disease, they undergo an intervention whether it's surgery or an intervention in the cath lab and think they are fixed and they have no further needs for cardiac surveillance. So, they maybe fall off the radar of getting followed because they feel so good. But, you know, feeling so bad is not necessarily a you know, like a foolproof issue, because a lot of patients feel so good until they really get to the stage which really are in dire straits, and, you know, we are kind of discouraged in how can we help this patient? Is it too late to help these patients, do they need transplant? So that you know, so part of that issue is that encouraging them to have lifelong follow-up from the get-go even as they grow, you know, from pediatric group to the adult group. And having a good, what we call transition or handoff, from the pediatric cardiologists to the adult culture cardiologist, where they, you know, discuss the patient paces, they share the records, share their course of care, so that the you know, the person who is receiving the baton can continue that race and following with the patient. So, I think education of the patient, make them aware that they're having congenital heart diseases, the condition

is going to be with them lifelong. There are simple ones, and you know, simple version of congenital heart disease that may not require as frequent visits. And there are more complex, congenital heart diseases that require maybe sometimes every six months instead of every year, or even sooner, depending on the case. So, I think education alerting the patients from the get go that you've had the heart condition, so this requires lifelong follow up, please maintain your insurance coverage, because I think part of the issues that we see patients fall off the crack is, you know, they have no access to care, they lost their insurance, it's you know, getting insurance is quite pricey at depending on the stage of life, what their work situation is. So, all these things, I think, I always encourage our patients to maintain their health insurance, and then always keep tabs, you know, if they move to a different city, you know, find the cardiologist, they have a heart disease, kind of get an updated visit, just to see, and again, it may be something we'll say we'll see every three to five years, or something. You say, no, you have a little bit more complicated issue, let's see you once a year or so. So, I think educating the patient as a child, getting the parents of the patient tell them you know, yes, he's an adult and is going to be independent, but this is something that's going to be with him throughout his life and requires lifelong follow up. So, hopefully, that's one thing. Yes, go ahead.

 Dr. Halena Gazelka 09:15
No, you please. Go ahead.

 Dr. David Majdalany 09:52
So, I think that's, that's the only thing is in trying to encourage access to care, I think, you know, now we have lots of resources online, where you know, even if patients go to different cities, they can find like on the, you know, ACHA website, they can say which providers are available in the city that have expertise in congenital heart disease. They can hook up with someone who knows their congenital heart disease, you know. I think sometimes they get scheduled with a general cardiologist, but may not be as familiar with this, you know, the long-term effects of the congenital heart disease. So, I think looking online for providers that have, you know, board certification and training in congestive heart disease in the city they move to is important so that they can maintain, you know, a follow up. And it's very important for patients to keep track of their medical records as they go from one provider to another. So, everyone kind of opens a new chapter in their book, I guess, of cardiac care. So, you know, things don't get lost, information doesn't get lost, and they have the optimal follow-up.

 Dr. Halena Gazelka 12:50

David, you touched on a topic which is a big concern to all of us at Mayo Clinic, and nationally now, disparities in health care. So, individuals who may not be able to maintain their insurance or may have difficulty having access to care, just as frequently with adults with congenital heart disease.

D Dr. David Majdalany 13:10

Yeah, I mean, it's unfortunately, it's not uncommon that we see that. And again, a lot of these patients say, Well, I saw the cardiologist, yes, I was 16, I felt good. So, I never really sought help to see anybody, then you know, they're unemployed, they have no insurance and then I don't feel so good. I need to see somebody. And then they just say, Oh, you know, can you pay deductible? Can you pay this? So, there are financial stresses on the patient that have delayed their care, and then they only come to us in dire straits in the emergency room, you know, whether it's over a heart failure, or irregular rhythms of the heart, you know, these are both very common sequelae of their congenital heart disease. So, it is true, and I think, you know, the adult congenital heart population is an underserved population in the means there's more patients than there are providers, and then depending on where they live, you know, some places may have one side that's six hours away from them that has congenital expertise. So, I think the as I mentioned, access to care, and then, you know, again, unfortunately, depending on where you live, you may or may not be an underserved area, but you know, and I always encourage our patients, you know, you can see us once every, you know, once a year or every other year, and then we can collaborate with your local cardiologist to optimize your care, especially if you cannot come in regularly to see us.

D Dr. Halena Gazelka 14:24

And I would imagine that that lack of access to care may contribute to more complications for patients who could have been treated at an earlier stage, that perhaps you see patients who have developed complications that wouldn't have necessarily had to occur.

D Dr. David Majdalany 14:41

Now it's there in some of the more complex versions of adult congenital heart disease. A lot of patients come when it's really too late for us to help them, we say the only option we have for you at this stage is you know, considering heart transplant or heart and lung transplant, or you know, advanced support, heart failure support devices. Had they presented to us two or three or four years before, we may have been actually able to fix their leaky heart valve without really causing significant weakness of their heart, not too

late to actually do anything.

D Dr. Halena Gazelka 15:13

So, one of the morals of the story might be, don't delay care, we're seeing a lot of delay of care during the COVID-19, in particular cancer care, primary care needs, cardiac care needs, but clearly care should not be avoided or delayed during this time.

D Dr. David Majdalany 15:32

You know now with the COVID pandemic, you know, we've been trying to manage our patients, if they cannot come for the in person visit, we kind of do these video visits, and we can communicate with them. And if I just said I'm concerned about you, I think an in person visit is really important, because you know, some of the things I cannot really address, I cannot exam you to see where you are in terms of your symptoms, the severity of the issues, we should certainly have you come back, you know, certainly take the precautions necessary to prevent exposure as much as possible. But you know, it's always risks and benefits. But I think certainly, if someone is not feeling very well, I usually like to see them in clinic. I like to examine them, talk with them, and then kind of share my thoughts face to face instead of being distanced through video.

D Dr. Halena Gazelka 16:16

But it is marvelous that these virtual visits are opening up the possibility of seeing a specialist that some individuals may not have otherwise.

D Dr. David Majdalany 16:26

No, it's true. And I think it's very important. I mean, we can have a lot of our patients have their studies done locally, and they can send us the images that we can review. And then we can communicate with them and their provider to kind of manage and kind of maintain continuity of care and share our expertise with their local provider, as well. So, I think it's, you know, from a congenital perspective is very important. And I try to be as collaborative with their local cardiologist as possible, sharing the information, sharing my thoughts. Also, that we should do this and this study at this point, if they cannot come to see me at this point, we'll be able to order them and they send us the results, and we can kind of try to rectify any issues in between when they cannot come for a face-to-face visit.

D

Dr. Halena Gazelka 17:06

A little bit earlier, you were talking about that transition from a pediatric specialist to an adult congenital specialist. Is there an ideal age or time in life when that should occur? How does the patient know it's time to seek a new cardiologist?

D

Dr. David Majdalany 17:22

Well, I mean, again, getting back that, I mean, in terms of pathways, you can get into adult congenital heart disease training, you know. We can approach it from both someone who is trained in adult cardiology, and someone who is trained from pediatric cardiology. And I think a lot of a lot of these patients usually start when they get in their teen years, it's probably a good idea to tell them, you know, you are certainly advancing in a different stage of life. Unfortunately, we don't get younger, we only get older. Time goes in one direction you know. I use it to advise patients, when they get kind of, you know, 13-14-15, or think about, you know I'm certainly, you know, approaching adulthood. And then maybe their cardiologist says you know, part of the aspects of your disease may be better managed with somebody who sees regularly adult patients. So, I usually think mid-teens probably is a good time to tell them, you know, start thinking about an adult provider, maybe give them names, different people, they can, you know, check them out online, they can check on their website, about their, you know, the qualifications and training. And then you should bring the records on the first visit and share with that cardiologist and kind of see is that somebody you really want to be kind of, you know, I always think as the physician, I'm the navigator, the patient is driving the car, and I'm navigating on the side is that the navigator you want to navigate your path through the rest of your life? I think communication between the previous provider and their upcoming provider is very important. And I usually, again, call them say, hey, I've seen your patient, you know, I think these are upcoming issues we're going to deal with. And then, you know, tell the patient and communicate with the provider this so they don't feel like they were abandoned by one provider and then oh, here's the other guy. Now I'm going to deal with a new person there. And developed this rapport. Because, you know, patients in the pediatric age group, they really are very bonded to the provider, because they've taken care of them from baby onward, it's like why are you leaving me alone? So, I think again, with the aspect of pediatric cardiologists who treat adult congenital heart disease, as well as adult providers, so we can still comanage the patient and maybe we can collaborate on their care. And then if there's some more aspects of the heart disease that's more adult related, maybe the adult provider can give them a little different perspective or unique perspective that pediatric cardiologist may not have that perspective that we have. So, I think it doesn't mean they're abandoning them. I think we can still collaborate and then different aspects can be managed by different you know, the provider that may be more attuned to see those issues.



Dr. Halena Gazelka 19:50

So, perhaps two very important points from that would be plan ahead and what we call a warm handoff in medicine where one physician or provider speaks to another and hands off the care to assure that smooth transition that you talk about.



Dr. David Majdalany 20:05

It's good to collaborate. And I mean, you know, some pediatric cardiologists still want to hear about how is my patient doing. They say, I've seen your patient, they're doing fine, or there's some issues we're dealing with at this time. And I think it's, you know, in congenital heart disease unfortunately the population is so small, we don't have a lot of research driven data. So, seeing different providers may give you a different perspective. And there'll be multiple correct answers to the right question whether we continue to observe, or we need to intervene, you know, you can see different providers and 50% of them say this and 50% say that. So, I think getting a different perspective is also a good thing for our patients so they can get, you know, they don't just get one sided view of what their care should be.



Dr. Halena Gazelka 20:41

I wanted to go back to a topic that you mentioned a little bit earlier about pregnancy. What advice do you give to women? What must they consider if they have adult congenital heart disease, and they're considering a pregnancy?



Dr. David Majdalany 20:55

Well, again, getting back to it, you know, with the advancements of medical care, a lot of these patients are getting into adulthood. And again, part of the security is I feel well, that means I can get pregnant. And you know, certainly it's a good thing that you're feeling well, but you know, pregnancy poses different changes on the body, you know, I call them physiologic and hemodynamic changes. This is a fancy word. But usually what happens is during pregnancy, there's increased blood volume in the body, there's increased demands on the patient's heart to increase the heart rate to increase the output of the heart. And depending on what congenital heart disease you've had and what is the status of your heart that was before you get pregnant, you're always wondering is this patient's heart going to be able to adapt and the patient have an uneventful pregnancy and have also a healthy baby. So, you know, heart disease and pregnancy are certainly one of the number one causes of maternal deaths. And you know in the United States, congenital heart disease comprises a large portion of the patients with heart disease during pregnancy. So,

I always say, you know, I will tell patients, again, depending on the complexity of your heart disease, it's a good idea before you contemplate pregnancy to come in, have an updated visit. Let the heart doctor listen to your heart, maybe do some basic imaging like ultrasound imaging of the heart, EKG, maybe an x-ray. And again, depending on the results, you know, whether we do stress tests or other imaging like CAT scan, or MRI, just to make sure your heart is in tip top shape before you get pregnant and you're able to sustain a pregnancy with low risk to the mom and low risk to the baby. And again, some patients we just say we just need to see you once or twice during pregnancy. Some patients, you know, they're more complex. So, we need to see you, you know, maybe two or three times in the first and second trimester. As you get to the latter stage of the third trimester, you know, where the highest demand on the heart and brains are current, you want to make sure you're able to adapt and your heart is adjusting appropriately. I mean, another point is that you know, certain medications are safe to take when you're not pregnant, but unsafe when you're pregnant. So, you certainly want to review the patient's medications, you want to make sure they're on medications that are safe to maintain, you know, for the pregnancy and not causing effects on the baby. You know, big issue would be some blood pressure medicines like ACE inhibitors are not safe. Cholesterol lowering medicines are not, you know, generally safe. Blood thinners, we certainly have to discuss what's the optimal blood thinning regimen, if someone is on a blood thinner, they have prosthetic valves and so forth. And issues like you know, enlarged aorta, aortic aneurysms, connective tissue disorders, these are other issues that we kind of discuss with the patient to kind of get a better feel of what the risks are to proceeding in pregnancy. And what are the risks to the baby because congenital heart disease does have genetic predilection, and there are certain types of congestive heart disease, that may be you know, 50/50 chance that the child may have the congenital heart disease or something similar to the parents. These are things we kind of discuss with the patient prior to trying to get pregnant, you know, becoming pregnant. And then we can say it's very important that we kind of follow you so often because you know, a simple disease would be not so often. More complex disease, especially in later stages of care will be, you know, more quick, maybe every few weeks. You know, in one of the programs we're doing is kind of having the adult congenital heart disease specialist, or cardiologists that have experts in pregnancy in heart disease, work along with their maternal fetal medicine, I mean, the obstetrician that's taking care of high-risk patients.

D

Dr. Halena Gazelka 24:29

I was going to ask you that. I would imagine that it matters what obstetrician you have and where you deliver your baby.

- D** Dr. David Majdalany 24:36
Right. So, I think communication between both providers is very important, because both share different perspectives. You know, safety of the mom, safety to the baby. And certainly, here at Mayo Clinic, we're trying to work so we can have a combined clinic so we can see patients ideally at the same time and kind of give them our perspective from both the cardiologists, congenital heart disease specialists, as well as the high-risk obstetrician.
- D** Dr. Halena Gazelka 24:59
Whole person care.
- D** Dr. David Majdalany 25:01
Yes, team effort.
- D** Dr. Halena Gazelka 25:03
That's great.
- D** Dr. David Majdalany 25:04
I think another thing I would recommend that a lot of these patients with congenital heart disease is seek expertise in tertiary care. Because their care is not managed by the cardiologist and you know obstetrician, I think sometimes we need to seek the advice, you know, of cardiac anesthesia, and, you know, particular, you know, obstetrics anesthesia, and if there's issues in terms for the baby risks, fetal arrest, usually we have our patients have a fetal echocardiogram done around 20 weeks of gestation. To have a strong pediatric team need, you know, neonatology intensive care unit team. You know, cardiothoracic surgery team or even, you know, our colleagues in the catheterization lab, because patients may need an intervention sometime, whether it's during the pregnancy or soon after the delivery. So. seeking care in a tertiary care center, that has all those expertise is, I think, another way to optimize the care during pregnancy and minimize the risk for both mom and baby.
- D** Dr. Halena Gazelka 26:00
You know, so often we talk about research that's ongoing as well. And I'm just wondering, is there any ongoing research in adult congenital heart disease?

D Dr. David Majdalany 26:12

I mean, it is, we are certainly part of it. We set up our database, and you know, I think part of the, you know, we were part of the international registry of patients with heart disease or congenital heart disease during pregnancy. So, we do share that information with international registry. So that, you know, we get to learn more. The more patients we take care of the more you know, the more our knowledge base will get better, and we can certainly make better decisions. And I think having a multicenter research project is very important. Again, as we mentioned, if it's 1% of the population that has congenital heart disease, if we combine the numbers of the different patients, different diseases from different centers, we can certainly have bigger numbers, we can get a more educated decision to help guide the care of these patients. So, multicenter care, international registries and sharing the research information is very important for our specialized patient population.

D Dr. Halena Gazelka 27:05

What an interesting area of medicine. Thanks for sharing with us, David,

D Dr. David Majdalany 27:09

Thank you very much Halena. Thanks for having me.

D Dr. Halena Gazelka 27:14

Our thanks to Dr. David Majdalany, cardiologist at Mayo Clinic in Arizona for being here with us today to discuss adult congenital heart disease. I hope that you learned something, I know that I did. We wish everyone a wonderful day.

N Narrator 27:28

Mayo Clinic Q&A is a production of the Mayo Clinic News Network and is available wherever you get and subscribe to your favorite podcasts. To see a list of all Mayo Clinic podcasts, visit [Newsnetwork.mayoclinic.org](https://www.newsnetwork.mayoclinic.org). Then click on podcasts. Thanks for listening, and be well. We hope you will offer a review of this and other episodes when the option is available. Comments and questions can also be sent to Mayoclinicnewsnetwork@mayo.edu.