Exercise Restrictions for Patients with HCM

Announcer: Welcome to the Mayo Clinic Cardiovascular Continuing Medical Education podcast. Join us each week to discuss the most pressing topics in cardiology and gain valuable insights that can be directly applied to your practice.

Dr. Hayes - Welcome back to Mayo Clinic cardiovascular podcast series, "Interview With The Experts." My name is Sharonne Hayes, I'm a non-invasive cardiologist, and vice chair of faculty development and academic advancement for the Department of Cardiovascular Medicine here in Rochester, Minnesota. Today I'm joined by Dr. Kathryn Larson. She works as an advanced echo fellow and is joining our faculty in July with a focus on athletes and structural heart disease, as well as hypertrophic cardiomyopathy and their exercise advice. And so today's topic that we have for her are exercise advice and restrictions for patients with hypertrophic cardiomyopathy. Welcome, Kathryn.

Dr. Larson - Thank you so much for having me, Dr. Hayes. It's a pleasure to be here.

Dr. Hayes - So tell us a little bit just about some of the issues with hypertrophic cardiomyopathy. How prevalent is this? Why do I need to care so much about this?

Dr. Larson - Yeah, well, hypertrophic cardiomyopathy is the most common genetic cardiomyopathy that a cardiologist or a general practitioner will encounter. So we know that about one in 500 people in the United States is likely affected by HCM, and so it's common and commonly missed, especially among young patients who may be asymptomatic and unfortunately has a fairly strong and robust historical association with sudden death. I think we can all kind of think back on unfortunate situations of, let's say, high-profile athletes or important individuals, or even non-high profile athletes who die suddenly during exercise. And those situations, unfortunately, it's not common but not unheard of for us to encounter a new diagnosis of hypertrophic cardiomyopathy in those individuals postmortem. And that's never a situation that we wanna be in as cardiologists or as you know, adults, parents, family members, we wanna make sure this is something that we discover before it becomes symptomatic and before it becomes a problem. Because we know that patients with hypertrophy cardiomyopathy, really with good care go on to lead very full and normal lives as compared to patients without HCM. So it's an important disease for us to keep at front of mind, especially as we're seeing young patients who want to be active.

Dr. Hayes - The diagnosis of hypertrophic cardiomyopathy is beyond the scope of today's podcast but tell me why is exercise in patients with hypertrophic cardiomyopathy, why might it be problematic?

Dr. Larson - Yeah, no, it's potentially for a lot of reasons. And I think when you think back to just the basics of the diagnosis of HCM really that gets to the heart of a lot of it. So you can

imagine the structural abnormalities in a patient with hypertrophic cardiomyopathy, so small LV cavity size, the presence of obstruction if it's present, significant let's say mitral valvular regurgitation, things like diastolic dysfunction. Those are all just structural abnormalities that may contribute to not only exertional intolerance but risk factors for let's say syncope or bad worse outcomes with exercise like sudden death. The more kind of front of mind issue though really comes in terms of ventricular arrhythmias. So patients with hypertrophic cardiomyopathy may have increased incidence of non-sustained ventricular tachycardia or ventricular tachycardia, and those really are the problems that we want to think about very carefully in patients who exercise, you can imagine the environment of exercise with the catecholamine surges can certainly put patients at risk for developing whether it's a structural exacerbation or an arrhythmic exacerbation to their cardiomyopathy that can potentially be catastrophic.

Dr. Hayes - And how can we tell who's at risk and who is not? So we know that there are both genetic variants and other things that predict lower or higher risk, and we do a lot of testing to try to assess that. How do you go about assessing risk for exercise in these patients?

Dr. Larson - Yeah, well, I would say first of all, no one patient with HCM is alike, just like really any other cardiac condition. There's unique structural and functional components of the disease that can differ significantly between patients even though they may carry the same diagnosis. So I would say first and foremost, any risk stratification has to come with a very good foundational knowledge of the patient who's in front of you. So for us here at Mayo Clinic, that involves a very careful structural assessment. So a resting echocardiogram. But here we often do provocative maneuvers during even just the resting echocardiogram to try and elicit obstruction and evaluate the severity of obstruction because we feel that's a very important component of what may happen with exercise. And having a good understanding of the physiology there can inform those risk discussions. And then really kind of careful evaluation of arrhythmic risk. So using tools like cardiac MRI to evaluate for presence of scar and late gadolinium enhancement and Holter monitoring, and often we put our patients through exercise testing as part of routine evaluation here. And I think that's very important for us to understand the symptoms that patients might manifest with, heart rate responses, the effect of therapy and also the presence of arrhythmias that may not be manifest at rest but may become more obvious with exercise. And so I think kind of like so many topics in cardiology, if you want to know about what's happening or what could happen with exercise, it's about testing that patient with exercise and then having a good understanding of the pathophysiology that's happening in those situations. And so really I think all of what I've said mimics the same situation we might be encountering when we discuss things like ICD implantation in these patients. I mean, really the risk factors oftentimes are the same which inform our risk with exercise. So I would say if you kind of work through the mental framework in terms of risk stratifying for ICD, for the most part, you're gonna encounter many of the same types of questions we might try to stratify with in terms of exercise.

Dr. Hayes - So once you've risk stratified, so you've got somebody who has higher risk, and maybe even you've elected to feel like they're high enough risk to put an ICD in, how do you counsel patients, low, medium, high risk, how do you have that conversation with them about future exercise habits?

Dr. Larson - Yeah, well first I would be remiss to say that this is a complicated discussion and perhaps one of the most complicated discussions that I've encountered with patients, simply because so much of it is ultimately unknown and the outcomes that we're worried about are potentially very rare outcomes but potentially catastrophic outcomes. And so that can be a very challenging thing to work through with a patient and to try and counsel about and educate about. And even for us as providers, right, to appropriately gauge risk and potential outcomes can be a real challenge because these can become very emotional discussions as well, especially if it's a patient who is dead set on remaining in competitive athletics or a type of occupation where they're gonna be exerting themself. We really wanna be mindful of the potential consequences of our counseling. And I would also say it's an area where the field has evolved a lot. I mean, even in the past couple of months, even within the last month, there's been new data to say that the risks of exercise in patients with well-treated and relatively minor manifestations of HCM may not actually increase the risk of sudden death. And so it's also a field where there's a lot of evolving knowledge and I think we have to be frank with our patients about that as well. I think when you're discussing this with a patient though it's most important to have a good understanding of where they're starting and where they want to go. What are their goals and motivations? You know, a patient who wants to go out and walk their dog around the block three or four times is very different than the patient who wants to return to professional athletics. And so the discussion has to be different as well. And I think really having the knowledge and expertise of the demands that are placed on those patients, especially at the higher levels of exercise, is important. And I think at the end of the day, at least here in the United States, those decisions are made at the patient level. We can inform them as much as we would like to, but you know, what the patient chooses to do or not to do is ultimately the decision that they take with our counseling. And so I think it's important to keep that in mind as well. Historically, I think the field used to be a lot more restrictive and dogmatic about restricting patients from exercise but I think what we've learned is we've maybe done a little bit more harm than good, especially in patients with low risk HCM in terms of promoting sedentary activity and the consequences of that. So the field has definitely evolved.

Dr. Hayes - So if I'm a general cardiologist who's got some patients, who maybe have carried a long time diagnosis of hypertrophic cardiomyopathy, they're stable, would there be a role for them to perhaps revisit previously given advice about physical activity with a sports cardiologist? It sounds like, from what you're saying, is if I was a patient and I was diagnosed 10 years ago and told you can walk your dog but don't do anything much else and I had wanted to run a 5k that maybe that might be possible now and at least to revisit the risk stratification.

Dr. Larson - Yeah, no, I think that's a fantastic point, Dr. Hayes, is that this field has changed really dramatically with some new data that we've seen. Again, like I said, even in earlier in May, there was an excellent paper that was published in "JAMA Cardiology," which I would refer anyone listening to this recording to go through and read which really did the first kind of very large prospective evaluation of patients with relatively well-controlled hypertrophic cardiomyopathy or what we would call, let's say genotype positive, phenotype negative HCM, and then looked at the risk of sudden death or really bad outcomes based on the level of physical activity. And what we saw is those really at the highest levels of physical activity did no worse

than the patients who were sedentary or mildly or moderately active. And I think that data is certainly still imperfect and incomplete, but absolutely, I think to your point, the patients who were maybe seen 10 or 15 years ago and told, you have to be sedentary for your own health and safety, I do think that discussion has evolved quite a bit based on some really good data and very thoughtful data that has come out in the last, I mean, like I said, as little as a few weeks ago, but over the past many years.

Dr. Hayes - Well, I think particularly with the known and growing list of benefits of exercise, mental health, depression in addition to healthy aging, and not falling, I do worry in my own practice with patients after coronary dissection who are often told some of the same things, do we really want to tell a 35-year-old woman, don't do anything for the next 50 years because she may be tipping over breaking a hip at age 65. And I would think many of these patients in my recollection, were really told, don't do anything.

Dr. Larson - Yeah, yeah. No, I think you're spot on. It's certainly, again, weighing the risks of the patient in front of you with what we know about the population as a whole and that really all of us should probably move more, both for our heart health, but also for other domains of our holistic health. And I think, to your point, being conscientious of the potential cardiac complications but the potential for non-cardiac complications of a sedentary lifestyle is also really an important consideration as we counsel these patients.

Dr. Hayes - Yeah, 'cause it's a whole lot easier to say no or never than the nuanced discussions that we really should be having that are evidence-based and patient-informed.

Dr. Larson - Yes, yes, absolutely, absolutely.

Dr. Hayes - In terms of other things we have to offer patients with hypertrophic cardiomyopathy who may have some symptoms, maybe they don't fall into this group that's phenotype negative or well-controlled. What things might we able to do so that they can do more than just sit around?

Dr. Larson - Yeah, no, that's a fantastic question. And again, a question that has changed dramatically in the past couple of years, with new classes of medications that have come out which are aimed to, let's say, reduce the vigorous contractility that we often encounter with patients with hypertrophic cardiomyopathy. So there's an entire class of medications that are now available either through clinical trials or through clinical practice, which have really, I think potentially changed the field quite significantly. And it's still a little bit early, but I think new ways for us to manage symptoms, new tools in the toolbox, so to speak, and patients who use these medications certainly feel better. And I don't think it's as robust for us to know the very longest term outcomes yet. But there's really a lot of new tools out there that we can use in these patients beyond our typical beta blockers, calcium channel blockers, which still may have a very important role especially in patients who are kind of just on the border of being symptomatic. What I think is important though is when you think about these patients who were followed in a

lot of these recent trials to look at potential long-term outcomes, the patients who were followed during those studies were followed like study patients, right? They were followed very closely at high volume centers, had frequent follow-up and careful attention to medications and titration. And I just think we have to be mindful too that a lot of the good outcomes we saw from some of those data probably had to do with the fact that those patients were followed very closely and put on careful medication therapy when needed. And so if we wanna kind of recreate or duplicate the good outcomes that we saw in some of the data and some of the publications, we really have to be seeing patients with relative regularity and have a good understanding of their baseline levels of function, how the medications have been helpful. And I would say also it's just important to keep in mind that a lot of our medications are aimed at symptom management but really are not necessarily targeted to lower the risk of sudden death. Those discussions happen more so in terms of the implanted cardiac defibrillator heart rhythm side than they do necessarily with symptoms and medication. So that discussion I think is important to kind of keep in mind that those often happen in parallel or both are important, but one does not necessarily perfectly translate into the other.

Dr. Hayes - So what I hear is a lot of optimism that we can apply some of this newly acquired information and treatments to improve quality of life, that they may not protect against sudden cardiac death, but we have tools for that and that people, both cardiologists and patients should stay tuned and stay hopeful that that there will be more to come, particularly as we push some of these therapies out into the real world out of the clinical trial world.

Dr. Larson - Yeah, no, absolutely. And I think there are two, just seeing patients recently, let's say, who hadn't been seen in a number of years and had been kind of living with mild symptoms, let's say exertional dyspnea, or some mild exercise intolerance if they had been seen three or four years ago, they're coming back now and there's a whole lot of other options on the table for them where there weren't necessarily anything different before. So again, I think just outlines the importance of kind of regular follow-up with someone who has expertise in that disease and that pathophysiology because they're gonna be the ones who are the most up-to-date and provide the most up-to-date counseling for those patients and probably have access to the most up-to-date treatment options for them as well. But yes, I think at the end of the day, incorporating exercise into the lifestyle of a patient with HCM is a huge point of clinical discussion, and really needs to form an important factor when you're seeing these patients for clinical follow-up whether in a special expertise center or in the general cardiology practice as well. I think it's a discussion that any cardiologist can have, and certainly the factors can get complicated but an important one that I think to keep on your list of to-dos when you see a patient with HCM.

Dr. Hayes - Well, I am really appreciative of you sharing your expertise today and really looking forward to you joining our faculty as a colleague both with your expertise about exercise and hypertrophic cardiomyopathy. Thank you so much, Dr. Larson.

Dr. Larson - Thank you.

Dr. Hayes - Yeah, this wraps up this week's episode of "Interviews With The Expert." Thank you for joining me for this important topic and we look forward to all of you joining us again next week for another "Interview With The Experts." Be well.