

Theodore Abraham, MD:

Welcome to this hypertrophic cardiomyopathy podcast titled Exercising with HCM. This is one of a series of podcasts from the American Heart Association HCM initiative, sponsored by Bristol Myers Squibb. I'm Dr. Abraham professor of Medicine at University of California, San Francisco, and have the pleasure of moderating this podcast. I'm delighted and honored to have with me two experts on the topic of exercise with HCM. Dr. Sharlene Day is associate professor of medicine and director of translational research at the University of Pennsylvania. And Dr. Martinez is director of Sports Cardiology and co-director of the Chanin Mast Hypertrophic Cardiomyopathy Center at the Gagnon Cardiovascular for Institute of the Atlantic Health Morristown Medical Center.

Theodore Abraham, MD:

Thank you both for your time and expertise this morning. Also joining us today is Brian Metz, a HCM patient from Colorado. Brian, we're very grateful to you for taking the time to share your story and viewpoints with us, Brian, as a lifelong athlete, having played tennis and being an avid hiker from school onwards was continued a very high intensity athletic lifestyle until he noticed problems with exercise tolerance that coincident with his diagnosis of HCM. I'm going to launch our podcast by directing my first question to Brian. Brian, explain to us briefly your athletic journey from high school and beyond. When did you first experience your symptoms and what were the recommendations made regarding your exercise practices after HCM was diagnosed?

Brian Metz, MD:

Yes, I played high school and college tennis while I was living in New York up to about six hours a day without problem, especially in college, we played singles matches first and then full doubles matches. So it could be up to a six hour match. No problem. I taught tennis in California during my college years and I would use my lunch break for playing tennis with one of the other teaching pros. We would play a singles match in front of the guests. So I could go 10 or 12 hours without problems. I moved to Colorado Springs after I finished my fellowship in 1997. And then in 2008 in the first half of the year, it was fairly abrupt onset. I like to run up and downstairs for exercise during my rounds or just other parts day.

Brian Metz, MD:

And I started having this unusual shortness of breath and some dizziness then followed by some very mild chest tightness at that time. I was still able to play tennis, but I would feel it. And living at 6,500 feet, I was just wondering maybe the elevation was contributing to it. I think the real wakeup call was when I was on a bicycle ride with my friend who's also a cardiologist at least 10 years older than me, but in very good shape. And I felt like I was going to die. I had this and usually severe shortness of breath and chest tightness and felt dizzy never was near syncopal . And from there I contacted my allergist just to make sure my exercise induced asthma from childhood wasn't becoming a problem again. And I had a normal methacholine challenge, which ruled out any asthmatic problems.

Brian Metz, MD:

And I think this is something that you all as HCM experts probably see frequent where asthma is the first thought in a lot of people. And then I was found to have a heart murmur by the same doctor who I was riding with, that showed just a proximal septal thickness of 1.6 centimeters. So not that thick. And I had a gradient with Valsalva in the 60s, had a stress echo, and my gradient went up to the 90s and the feeling was I had an early case of hypertrophic cardiomyopathy at that time. After my diagnosis was

made, I started a beta blocker, but I really had to curtail my exercise with playing tennis. I play in a 4.5 USTA tennis league. And the warmup I found was usually my worst problem.

Brian Metz, MD:

I felt most my symptoms during warmup. Caffeine aggravated a lot of my symptoms. If I had caffeine before I played, I didn't like a fast heart rate when I was playing and hydration was absolutely key. And I didn't do well with eating food two hours before I played. My recommendations that I received at that time were to avoid playing singles tennis and avoid specifically competitive tennis, if possible, and play mainly doubles tennis. And there were some guidelines at that point, and that came from a table that I'd actually seen at one of the conferences that pointed out that doubles tennis was the way to go.

Theodore Abraham, MD:

So, Brian, thank you for telling us about your exercise prescription at the time of your first diagnosis of HCM. Tell us briefly, how did that make you feel? Do you think the recommendations your cardiologist gave you were pretty clear or were they somewhat confusing also? How did you personally feel and take it when you were asked to curtail your exercise as you put it?

Brian Metz, MD:

Well, it was hard for me at the time. I was actually the captain of the USTA team, mainly because someone had to organize all these matches. It wasn't that I was the best player on the team, but I did a lot of the organization of who played and such, but either way, I felt an obligation to keep on playing because we had limited numbers of players. So when I didn't have to play, I didn't play, but when we needed people to play, I played doubles and I felt I had to be very careful. At times when I was overdoing it in my warmup, I felt like I could pass out. And I think I came pretty close at times. I just had fairly good habits of hydrating.

Brian Metz, MD:

I hydrated so aggressively had to run to the bathroom a few times during the match, just to compensate for all the fluid I was drinking. Hydration was my compensation. And I just avoided caffeine on those days. And I especially could not eat within the two hours before I played, but it was frustrating. I felt obligated to a lot of my friends. I couldn't explain this to a lot of people too. I think that's an issue for not many people really understand what HCM is about. It's a lot easier to tell somebody, oh, I just had a stent last week I can't play as vigorously. But to tell people that you have hypertrophic cardiomyopathy, that then they don't necessarily understand what your limitations are. And especially if they've seen you playing for all these years, they know you can usually play good tennis. And the issue with doubles tennis is it's a lot of sudden motion, you're poaching for a ball. That's a big stress on the heart with hypertrophic cardiomyopathy and brought on a lot of my symptoms.

Brian Metz, MD:

So it was very difficult. So I understood the recommendations, the chart made some sense to me. It's like, I think next to doubles tennis was moderate level ping pong or other sports like that. But I don't think things were completely clear for me, especially when I started hiking with my wife about five or six years ago. I really had to listen to my symptoms when I was feeling the chest tightness or shortness of breath or dizziness when going up hills. And again, I would hydrate like crazy, but I also felt obligated to my wife. I mean, as a husband, you feel obligated to be able to take your wife on a hike in the mountains to get some exercise. So it's definitely conflicting. You get the recommendations, you want to

follow them, but you also feel the need to maintain your athleticism with the sports you compete in and as well as obligations to your family and in activities too.

Theodore Abraham, MD:

I'm not going to turn to Dr. Day and ask you to comment about your experience with patients with HCM. Are most of your patients active or sedentary, and what are your recommendations at the first visit as to what a regular nonathletic patient should do or not do with regards to exercise?

Sharlene Day, MD:

Well, thank you, Dr. Abraham, for that question, I'm really delighted to be here in this today. The clinical practice standard and guideline recommendation for many years was, was that patients with HCM should be restricted from exercising vigorously or competitively because of a perceived increased risk of sudden death. And so I think the intent of this recommendation is always been inherently good. We want to protect patients from harm, but it was never really founded on any data. And I think there have been a number of unintended negative consequences, physical, mental, emotional, both for athletes at any level in high school and through adult life. And these patients have been, many of these patients have been subject to these type of restrictions for a long time. As far as my patients, I think they really cover a broad range of physical activity, some who are quite inactive and others who are competitive athletes at various levels and really covers the entire spectrum.

Sharlene Day, MD:

I think for those who are relatively inactive, I strongly encourage them to initiate a regular exercise routine. That's in keeping with the guidelines from the American Heart Association for overall heart health. This is about 150 to 300 minutes of moderate intensity exercise per week, walking, cycling, swimming, whatever the motive of activity is that they prefer. And I recommend that they build up gradually, that they give themselves plenty of warmup time, because patients with HCM often feel like they need additional warmup to be able to get to a certain level of comfort, that they hydrate well before, during and after exercise. And ideally that they not exercise alone in case something does happen, or they feel unwell that there's somebody there for them that can call for help. There really isn't anything I advise against doing, but I'd rather help them to attain their own goals, to get there gradually and use common sense to stop if something doesn't feel right, if they're dizzy, lightheaded or if they feel excessively winded.

Theodore Abraham, MD:

Thank you Dr. Day, very useful thoughts. Moving on to Dr. Martinez. I know you serve as a sports physician for several collegiate and professional teams. Once you have a diagnosis of HCM and these very high level athletes, what are your current recommendations about what they can do and cannot do? Also please comment about how you recommend regarding them continuing formal competitive sports.

Matthew Martinez, MD:

That's a great question, Ted. Thanks for having me, as we evaluate more collegiate and professional athletes, we are clearly going to identify more folks with hypertrophic cardiomyopathy. And Dr. Day mentioned the historic data where we've had a dichotomy where in prior discussions, that those at the highest level who were competing, hypertrophic cardiomyopathy was overrepresented in elite athletes who died suddenly. But we know that if you specifically, at data of studies that focus on hypertrophic

cardiomyopathy, we haven't seen that excess number of events on those based on effort and intensity of participation.

Matthew Martinez, MD:

So what we're doing now is what we do for most folks with hypertrophic cardiomyopathy and the first is to ask them what they want to participate in and what their needs, their goals are, what the expectations are. Because two pieces to this puzzle is those that are going to continue as athletes. And as you mentioned, those who are going to continue to participate in sport as part of their lifestyle. So first we're going to risk assessment. We want a complete evaluation. It's going to include imaging, echo cardiography, cardiac MRI, provocative testing, and monitoring to make sure that I have a handle on the individual risk in front of me, because there is no right or wrong. There's no specific answer to the patient in front of you. I have to approach each individual individually, as you might expect. And assess what that individual's risk is.

Matthew Martinez, MD:

And then we engage all as part of that discussion. And we have a discussion about the available data that includes gender race, the type of sport, and any disease specific risk factors that we identify. Anybody who sees me for HCM, we go through a risk assessment for them. And then based on that, we make sure that all are in the know. We're going to include the family, the player, medical staff at the institution, because all have some participation in this shared decision making discussion, something that occurs with HCM patients throughout their care, whether it's a defibrillator, exercise or another aspect of their care. So we're going to risk assess them and then include all of the folks who are part participating in their care and make sure that we have a well-designed plan for them, which includes things like warning signs, hydration, what their diet looks like, what the activity looks like and what the potential harm of that individual sport would be.

Matthew Martinez, MD:

And then finally, I can't end, without at least saying to you really important that we emphasize the emergency action plan and the AED as part of this. So these days almost all colleges and all professional teams have some emergency action plan and AED of course, part of that plan. But I reemphasize it and I also encourage the athlete to participate in their own care. And many of them are choosing purchase their own AED that they carry with them no matter where they're participating, because these days, many athletes are participating well beyond the supervised activities. And they're of course, exercising on their own and they want to be protected during those events. So whether they participate in sport or not, and I think people would be surprised about how many decide not to participate in collegiate and professional activities, there's still going to be an important discussion about the role of exercise and in their life going forward.

Matthew Martinez, MD:

And of course, just like the guidelines have done for years and years, encourage continued physical activity, mild to moderate exercise in all that are with HCM. And we can have more about that discussion later on. So it's not just whether or not they're competing at a collegiate or an elite level it's beyond that. And that discussion can continue for during their time as a collegiate or professional athlete. And then beyond that.

Theodore Abraham, MD:

Thank you, Dr. Martinez. So if I hear you correctly, just to follow up on those very thoughtful comments, you are not issuing a blanket prohibition of competitive sports at collegiate professional level, just based on the diagnosis of HCM.

Matthew Martinez, MD:

Yeah. So let me be absolutely clear that we're not talking about disqualification at all. What we're talking about is risk assessment. We're talking about evaluating an athlete and determining what their individual risk is, and then engaging them in that process for what their potential risk might be and what I think the harms and might be for them continuing to participate in sport, whatever that sport is, whether it's marathon running, triathletes, they're going to be a collegiate basketball player or a professional football player. We need to have a discussion about what that risk is. I don't like the term disqualification. I think it is somewhat inappropriate, but a discussion with the individual about what their risk is.

Matthew Martinez, MD:

And then we engage them along with all the other participants, including the institution of the medical team to make an informed decision and best care for the individual in front of me. Absolutely important discussion.

Theodore Abraham, MD:

Thank you. I'll move the next question on to Dr. Day. Dr. Day, could you please summarize the knowledge based on the current level of published evidence that supports a particular level of exercise intensity or conversely, does anything support the restriction of exercise in an average patient or at athletes with HCM? Also, can you briefly comment on any ongoing studies that you might yield additional information in this regard that might help clarify some of the issues and thoughts that Brian just outlined.

Sharlene Day, MD:

I would be happy to. So Ted until five years ago, there really weren't many data available to guide exercise practices in patients with HCM, a study called reset HCM was really the first prospective study published about five years ago. And it used a randomized controlled trial design to study the impact of moderate intensity exercise versus usual activity on exercise capacity. And the exercise prescriptions they were individualized and largely people were walking, cycling using elliptical trainer. They weren't doing competitive or very highly vigorous sports. And the outcomes were exercise capacity, quality of life. And then a number of other outcome measures. And the results I think were very reassuring in that there were no major arrhythmic events. There was really no signal for harm and exercise training resulted in a significant improvement in exercise capacity and also in physical functioning, on a self-reported quality of life survey from the patients who participated.

Sharlene Day, MD:

There are a couple of ongoing trials of high intensity exercise in patients with HCM. One of which has been reported in abstract form. And so far the results from these studies that I've heard have been reassuring, but we really need to wait for the peer review reports. There are two prospective studies, one from Italy and one from the United States of athletes with HCM, who've stopped playing and compared to those who continued competing, and these were competitive athletes in both groups, some stopped, some continued and both studies showed no increase in arrhythmic events in those

athletes who continued to compete. So that's also reassuring, but I think the numbers are still relatively small. So we need more data. There is an observational study called lifestyle and exercise in HCM or LIVE-HCM for short. And that's studying about 1,800 patients with hypertrophic cardiomyopathy across the spectrum of physical activity, including competitive athletes and the study completed follow up and hopefully the results will be available soon. So I think the study will provide important additional data to help patients and providers make informed and shared decisions about exercise participation.

Theodore Abraham, MD:

Thank you, Dr. Day. Dr. Martinez, you alluded to your approach to shared decision making, engaging the patient, their family, the level of intensity of the sport and the actual sport. Could you please comment on the 2020 HCM ACCHA guidelines, how do you think they address the exercise prescription issue? Where do you think they got it right? Where do you think they could go further in helping explain this to both clinicians dealing with HCM as well as patients facing the diagnosis of HCM?

Matthew Martinez, MD:

Well, what I love about the 2020 HAACC HCM guidelines specifically about this discussion is that we brought it to the attention. It's at the top of the page. It's part of what those of us are caring for HCM patients on a regular basis are doing anyway. So, it reflects an appropriate practice at really at an expert level. And remember, it's a 2b recommendation, not the recommendation to have shared decision making, but a 2b recommendation with regards to high intensity sports. But of course, mild to moderate exercise is still something that should be discussed with all HCM patients and continues to be encouraged. So, what they got right was that they continued to support mild to moderate exercise. They address the fact that there are folks that are going to compete at a different level than that. And that may want to compete at a higher level than that. But emphasize the fact that those who were considering that should be seen by those with expertise.

Matthew Martinez, MD:

This is an opportunity to engage a center of excellence with expertise in this specific arena, so that you can get an expert level discussion and have that discussion. In our practice, and I suspect the same in Dr. Days practice as many centers of excellence do an exercise. Prescription is something we do regularly. I do it with every initial visit and I do it at almost every routine follow up visit. And we talk about the moderate exercise, what that should look like, what that means, how you know if you're doing more than that, what those symptoms might look like, I engage the athlete, whether they're recreational, whether they should be recreational and need more recreational in their day or whether or not they're an elite level athlete, I want to know what they're doing and what their expectations are, what do they want to gain from it, rather than pretend it's not happening. I pull it out of them.

Matthew Martinez, MD:

I want to know what they're doing. I want to be able to discuss with them what that risk might look like based on the individual in front of me, I want to know about symptoms. I want to know if they're exercising with somebody and try and encourage that behavior. And of course we talk about diet and hydration and what they're doing to protect themselves from the other side of exercise. The diet and how they get prepared for it. So I would like to see a little more discussion about what that might look like, how diets impact those with HCM and continue to improve upon hydration. I think we need more data that's coming I think from many that are evaluating this, including high intensity intervals and all of that data to help us better guide in the next version of an updated guideline to help those who are doing

a little more than just that mild to moderate exercise. So it should be a part of every patient who is seen with HCM.

Matthew Martinez, MD:

I prefer the opportunity to engage the individual in what they're doing so that if they're having symptoms, that they know that we're open to discuss what that might look like. And again, as I mentioned before, it's not about disqualification. This is about evaluating the person in front of you and helping determine what their risk might be. Maybe they don't even realize they're putting themselves at high risk. So this is an opportunity to discuss it with them and something that should be done, I think, at every visit for an HCM patient, especially in those who are engaging in beyond recreational level exercise.

Theodore Abraham, MD:

Thank you, Dr. Martinez, Dr. Brian, we've not mentioned this earlier in the podcast, but you have a very unique perspective. Not only are you a patient with HCM, but you're also a trained cardiologist and a practicing cardiologist. Based on what you just heard and comments from two highly regarded and highly knowledgeable experts in the field of exercise and HCM, how do you think the messaging should be? What is the concise message and the clear message that you think you as a patient would like to hear, and you as a cardiologist would like to deliver regarding exercise in the setting of HCM? Putting more yourself in the perspective of the recipient of the information.

Brian Metz, MD:

I am reassured by hearing Dr. Day's the small trials that have been done looking at safety in HCM, patients competing in sport. And I'm glad to hear there are more trials going on looking at this because I think it is understudied. And I also enjoyed hearing Dr. Martinez's perspective of not trying to look at qualification versus disqualification, but really focusing on that exercise prescription. Obviously there are some risks involved with competing. And I think everybody has to understand there's a difference between going out. My current exercise now is going out in the tennis court and hitting with my double's partner. My double's partner got worried when I told them about some of the issues that we're going. I said, "Hey, I'm happy just to get on the court with you and hit and thus not compete because I realize you get into trouble when we're in a tight match and you're overdoing it."

Brian Metz, MD:

So having someone to speak about an exercise prescription, I think is extremely helpful. And I do think it is important that we start to help people with instructions on hydration and caffeine intake, food intake, timing before exercise, medications obviously, as I've been involved in my care with you, Dr. Abraham. And I think all of that put together will allow much better care of the patient, especially in HCM focused practices. I do think there are enough patients with all the variance of HCM that they should be seeking out care in HCM focused centers to get people with this experience. And as you know I've benefited from being able to come to UCSF and have my medication and care managed by your fine team. So all of this is very reassuring to me, both as a patient and as a practicing physician.

Theodore Abraham, MD:

Thank you, Dr. Brian Metz, appreciate your thoughts and perspective. I would like to now ask our expert panel to offer their final thoughts and recommendations to folks regarding exercise with HCM starting with Dr. Day.

Sharlene Day, MD:

Well, I think it's really interesting to hear Brian's experience and everybody's experience is different. And as Matt Martinez pointed out, these are really individualized discussions. And a conversation I would have with you, Brian is really different than a conversation I would have with a collegiate athlete who has absolutely no symptoms whatsoever. And his diagnosis, his or her diagnosis was made incidental. Picked up on screening, abnormal EKG or something of that nature. And so for those individuals they have absolutely no physical limitations. And so it's really a matter then of discussing, is there a potential increase in risk of sudden death that they continue to compete versus if they withdraw, if do recreational exercise. And honestly, the answer is not clear at this point. So far, the data are not pointing that direction, despite that it seems somewhat intuitive that maybe the risk would be higher because you're putting more stress on the heart.

Sharlene Day, MD:

But honestly the data are not so far pointing in that direction, but it's different to advise somebody who has symptoms and then what are the things that you need to be attentive to? And how do you sort of set your own limits to make sure that you don't pass out or to make sure that you don't get excessively winded and put yourself at risk from that sense? So I think the take home point, I think from this is that one, there are data accumulating, which is really encouraging and so far has been reassuring. We definitely need more and that these are individualized decisions. And I think the shared decision making approach is really the way that we should be going now.

Theodore Abraham, MD:

Dr. Martinez.

Matthew Martinez, MD:

Hopefully what you've heard during this podcast is that there is no standard HCM patient and that each one requires a different assessment. And what's clear to me is that we're going to find more and more patients with HCM as we're bringing awareness to its diagnosis, that whether you're a collegiate or professional athlete, we know we're going to make those diagnosis, the diagnosis of HCM and others. And what I want to be involved in is not disqualification, but making a diagnosis, having a discussion, a risk assessment, and then creating a plan for that individual that's in front of me. And what's also clear is that those with cardiomyopathies symptomatic or not are going to ask to participate in sports. And they do that because of all of the reasons we all know. There's benefit in both the physical aspects and the emotional benefits of being involved in sport, whether you are competing for a ring or whether you're competing to prevent cardiovascular disease, or all the other benefits that go with exercise.

Matthew Martinez, MD:

So engaging HCM, patients and others with cardiovascular risk to better understand who they are and make sure that we can best care for the individual really requires this sort of conversation and shared decision making is a huge part of how that's done.

Theodore Abraham, MD:

Thank you, Dr. Martinez. Thank you, Dr. Metz for your time and perspective. Thank you. Both Dr. Day and Martinez for offering your expertise, sharing your wisdom on this very critical, important topic. I don't think I could express it any better than the three of you have expressed it. Clearly we've come a long way and better understanding the impact of exercise and the risk of exercise in HCM. It is



heartening to know that it is safe for most part, clearly the risk needs to be individualized, and it is also very encouraging that there's emerging research and ongoing research that will help us even better understand what is potentially allowable versus potentially dangerous exercise in patients with HCM.

Theodore Abraham, MD:

Clearly we could talk about this topic for the next two hours and still not scratch the surface. This podcast is part of the American Heart Association HCM initiative, sponsored by Bristol Myers Squibb. And in closing, I would like to remind everyone listening to encourage your patients, to play an active role in their medical care, by advocating for themselves and for their family members. And to get additional information, please visit the AHAs hypertrophic Cardiomyopathy website for more education. Thank you all.