

Transcript Details

This is a transcript of an educational program. Details about the program and additional media formats for the program are accessible by visiting: <https://reachmd.com/programs/clinicians-roundtable/living-with-lymphedema-a-patient-perspective/12422/>

ReachMD

www.reachmd.com
info@reachmd.com
(866) 423-7849

Living with Lymphedema: A Patient Perspective

Dr. Chapa:

Welcome to *Clinician's Roundtable*. I'm Dr. Hector Chapa. Up to 10 million Americans and hundreds of millions worldwide suffer from lymphedema and lymphatic diseases. More people suffer from these diseases in the U.S. than suffer from multiple sclerosis, muscular dystrophy, ALS, Parkinson's disease, and AIDS combined. Although most known as a post-cancer treatment sequela, its occurrence is not limited to cancer survivors.

Bringing a unique and personal perspective to lymphedema is my guest, former reality TV persona, Cameron Ayala, as a lymphedema patient and lymphedema patient advocate and compression specialist, Cam knows first thing what living with lymphedema is like. Cam, it's a pleasure to have you. Welcome to the program.

Mr. Ayala:

Thank you, Dr. Chapa, I'm really happy and really excited to be here. It's going to be great conversation.

Dr. Chapa:

Cam, you have been very vocal and very public about your longstanding diagnosis of this condition, this lymphedema. Can you tell us a little bit about how your diagnosis came to be? Let's hear your story.

Mr. Ayala:

Sure, sure. So I'll try to be as succinct as possible, because for most lymphedema patients, it is a rather long journey. It's very rare that a lymphedema patient just presents with lymphedema. Oftentimes there's other pre-existing conditions or comorbidities or, as you alluded to in the introduction, lymphedema can be secondary to things like cancer treatment, for example. So for me personally, when I was around 11 years old, I started to have lower back pain when I was playing, Little League basketball. And so that led my parents to taking me to an orthopedic doctor, which in the initial imaging of the x rays, they noticed there was a leg length discrepancy. So my right leg was about an inch and a half shorter than my left. And he also noticed some peculiar spots on my right distal femur that via the x-ray, he said it could be cancerous, so let's go and do a bone biopsy. So in that bone biopsy on my right distal femur, the presentation was basically just a hemangioma of the bone. So, basically nothing. It wasn't, you know, cancerous or anything too alarming.

But that surgery itself was what is considered to be the triggering event for my lymphedema. So about one week, two week, and about a month post-op as I was going through and doing the physical therapy, as most patients do when you have really any type of orthopedic surgery, you know, range of motion, strength and conditioning, and really just rehabbing that knee postoperatively, my right leg just continued to progressively swell.

And I even had a lot of physical therapists at the time tell me that, 'Oh, Cam, that's totally normal. Your muscle tissue is building. You're getting stronger.' But really, it felt like the inverse. I often associate the symptoms that I was experiencing, similar to people who've just kind of rolled or sprained their ankle, either if it was through sports or just kind of that walking around. So that trauma. And it literally took me about a year. Now, bear in mind, this is in Houston, Texas, in the medical center. I'm going to all the different major facilities and specialty clinics, even went to the Shriners Hospital where they had a geneticist run some genetic tests. And those genetic tests then led them to send me to wound care. And I didn't even have an open wound. But the wound care specialist was able to very quickly identify, yes, you present with primary lymphedema.

So I think for a lot of lymphedema patients, the journey to even getting the diagnoses is really challenging because it's something that I'm sure even you can attest to, Dr. Chapa, that the lymphatic system, not even lymphedema, but the lymphatic system is something that is not really covered at length in medical school. Is that something you can validate, Dr. Chapa, from your personal experience?

Dr. Chapa:

For sure. And I have to be honest, and I think many physicians can relate to this, Cam, is when I hear lymphedema, although we know and we learn microbiology and we're aware of the parasitic infections, you know, worldwide with elephantiasis and things of that nature, when a physician typically hears lymphedema, and I think most of the audience can validate, what do we think of? We think, oh, that's a post-cancer issue, but not always the case, Cam, as in your story. And that's kind of what we kind of box in that condition to a certain area of medicine, like that's oncology. But not the case as you have very well stated.

So tell us more about this, because I think this is going to be eye-opening for a lot of people that, stop relating this to sub-Saharan Africa with elephantiasis, or those are just cancer patients. So, that's really where I think it's going to be eye-opening. Cam, tell us more about it.

Mr. Ayala:

Yes. So just on the whole notion of primary and hereditary lymphedema, that's what I present with. So these patients can have their lymphedema be latent for a vast majority of their lives. Right? So take, for example, even a breast cancer patient. Right? You take two separate breast cancer patients. You have the same staging of breast cancer. They go to the exact same oncologist. They receive the same amount of chemo, same amount of radiation, and maybe even undergo the exact same type of surgical intervention. So why is it that only one of those patients develops post-cancer lymphedema, whereas the other doesn't? Well, we now know that there's a genetic pre-deposition, and with stage zero lymphedema.

So that's something a lot of physicians need to understand. There is such thing as stage zero lymphedema, where essentially the patient is asymptomatic. They're not having the swelling of the, extremities. They don't have the pitting edema. And some of the stemmer signs and some of the other key diagnosing features that a lot of, physicians will look to give that clinical diagnosis of lymphedema.

But now we've come so far, even just the imaging of the lymphatics where, with new procedures like indocyanine green that stands for IC green lymphatic imaging, we can now look at a patient's lymphatic anatomy from the lymph vessel and even the lymph nodes to determine if this patient either already presents with lymphedema or if they're Stage 0 and they're at risk for establishing it down their line. So, for example, if you have a cancer patient and, before you're doing any of these treatments, I think it's really important to consider those types of imaging procedures. That way, when you're proactive with treating lymphedema, you can really substantially impact a patient's quality of life because you don't want to wait until they're stage two or stage three, where it's much harder to get that volume down and to give that patient a better quality of life because it's something that could have been handled a little bit more proactively.

Dr. Chapa:

See, that's something that's eye-opening right there, because I wasn't aware of the genetic biomarker. So in other words, what BRCA, is to breast cancer as the breast cancer gene, so to speak, there seems to be now a certain gene or a collection of gene, Cam, for congenital lymphedema. Tell us a bit about that genetic tie. Yours is hereditary, correct?

Mr. Ayala:

Correct. And I'll even go down to the vascular side of things, because take, for example, when we're in our embryonic phase. So we're about seven weeks into our development, our lymphatic system and our vascular system are essentially maturing and mutating at the same time. And there's even a vein called the cardinal vein that basically branches out. So basically, if a patient has a family history of lymphedema or even vascular diseases, venous insufficiency, varicose veins, spider veins, any of those malformations of the vascular system, that patient is genetically predisposed to establishing things like lymphedema. So I thought for years that one of the leading causes of secondary lymphedema was due to cancer patients, that what we were talking about earlier. But actually, we have updated studies that show the leading cause of secondary lymphedema is actually chronic venous insufficiency. So once those veins are at a point where their valves aren't working and that interstitial fluid is not draining, the damage has been done. And that patient now presents with secondary lymphedema. So they wonder why they're going to their cardiologists or their vascular doctor and they may just be put on diuretics to treat the lymphedema. And that is not going to do the trick. That's like going to get your oil changed at a mechanic, and instead of changing your oil, they change the wiper fluid. It's a completely different fluid.

So though diuretics are great for other applications, diuretics are not intended to get the lymphedema swelling down. And so a lot of vascular and cardiovascular doctors and really just general physicians who are prescribing diuretics for lymphedema need to understand that is not its application and not the main use.

So, again, lymphedema is not a one size fits all condition because the lymphatic system literally touches from our toes to the tops of our head. There's lymphatic fluid everywhere, even in our brains. Right? So we're starting to see more studies come out that show, if a patient has an impaired lymphatic system, can that contribute to things like dementia and Alzheimer's? So, we're really in the Wild West when it comes to truly understanding not just lymphedema, but the lymphatic system in its entirety.

Dr. Chapa:

You're listening to *Clinicians Roundtable* on ReachMD. I'm Dr. Hector Chapa and I'm speaking with Cam Ayala about his experiences not only as a patient with lymphedema, but also his advocacy about this condition. Now, Cam in your professional career, you're a lymphedema compression specialist. Tell us a little bit more about that therapy, how it's helped you, and how it can improve quality of life for other patients with the condition.

Mr. Ayala:

Absolutely, so I work for a company called Lympha Press. And Lympha Press is one of the pneumatic compression pumps on the market. And for those who aren't familiar with pneumatic compression pumps, essentially there's garments that can be applied really to any part of the patient's extremities, arms, legs, abdominal, even head and neck. And this therapy, this compression therapy essentially helps facilitate lymphatic flow where patients are otherwise refluxing or that fluid is just being stagnant in their arms, legs, or wherever on their body, that has caused the lymphedema.

And what I do every single day in the field, is I go around the greater Houston area, educating cardiovascular doctors, podiatry, wound care doctors, nurses, and even certified lymphedema therapists who work more in the outpatient space about the value of, pneumatic compression devices for home therapy. Because the fact of the matter is that there is currently no cure for lymphedema. There's a couple of innovative surgical techniques that are being done across the globe that are still somewhat new. And there's still a lot of, I guess the jury is out in terms of long-term efficacy, and they can make patients drastically improve symptomatically. But I tell my patients, when I'm dealing with them, look, gravity and lymphedema don't take any days off. So the more consistent you are with your compression modalities, whether it's a compression pump, like the Lympha Press, whether it's your compression garments that you're wearing on a daily basis, or seeing people like your certified lymphedema therapist, it's really all a part of this, what I like to call compression ecosystem. That's not only necessary, but really effective in improving these patient's quality of life where if they don't, they're at the risk of things like cellulitis infection. The lymphedema can get to a point where it - their mobility is drastically impacted, which can lead to obesity and a whole array of other medical conditions that can spur from that.

Dr. Chapa:

Now, is this compression therapy, is that more preventative or is that, once it's established, then compression therapy is now utilized? Or is it both?

Mr. Ayala:

It's actually both. So, you know, like with any really health condition, the earlier you intervene, the better, right? You can prevent progression. So we have seen a lot of cases where a patient may have been on that teeter between stage one and stage two lymphedema, but we started to get them using active compression, like using the pumps, like using the garments, and doing the wraps with their lymphedema therapists. And they can actually bring down the volume of their extremity, facilitate that lymphatic flow, and bring them down a stage. So there are certain parts of lymphedema when you start getting to the deeper stages, like the Stage 3 or Stage 4, depending upon your staging that you're utilizing, that becomes very difficult and, in some cases, near impossible to reverse.

You mentioned earlier things like elephantiasis. So those patients who have really, really fibrotic tissue and their extremities are so, so large and they start growing lobules and other lymphatic masses to where there's just no circulation flowing, where sometimes it has to result in amputation or pretty drastic debulking procedures.

Dr. Chapa:

Now, one other thing with the compression is this put on daily, is it weekly? And do you still use this, Cam?

Mr. Ayala:

So short answer is it's daily. Right? And I was saying earlier, lymphedema is not a one size fits all. Right? So the patient has other pre-existing conditions where active compression may not be appropriate. You know, those are more of the, you know, anomalies and outliers than the norm. But typically, most patients are required to wear these forms of compression daily, and in some cases 24/7.

So me, for example, when I wake up in the morning, I have a daytime compression garment that I put upon my right leg, which is about 30 to 40 millimeters of mercury gradient compression. So that's how we measure pressure when it pertains to pumps and garments is millimeters of mercury. So I wear a 30, 40 gradient stocking that goes all the way up to my hip every single day throughout the day. So I'm on my feet a lot in clinic or I'm going to patients homes and doing therapy there. So then at the end of the day, I remove my garment, and as I've showered and getting ready for bed, I even have a nighttime garment that's a little bit more padded. It almost kind of looks and feels like an oven to give you that sense of what that garment feels like. And I even wear my pump Lympha Press pump on top of that. And I pump only for about an hour in the evening time. And that really just kind of gives me that final sweep and helps break down some of that fluid that may have been accumulating throughout my day and through gravitational pull that is never ending as I say.

So again, for most patients, this is something they're going to have to do every day. So lymphedema is a condition that takes a lot of self-discipline, a lot of consistency, because if you aren't consistent - I view my lymphedema in terms of risk-reward analysis. Right? So what are the risks if I decide to go to the beach and not wear my garment or I decide to go to a concert and not wear my garments, or maybe I go several weeks without pumping. Right? So it's basic fluid dynamics. If you don't compress, the fluid will be stagnant, and it will expand. And then you do not want to deal with these chronic wounds because that is this vicious cycle of the wound's never going to close, because the edema is going to continue to manifest and it's going to continue to expand, making wound healing a very, very difficult challenge for these patients.

Dr. Chapa:

Very, very practical advice, and very real world. And lastly, Cam, I know that you're proud to be a patient advocate. Tell us a little bit more about the LE&RN, or the L-E-and-R-N, LE&RN national program.

Mr. Ayala:

Yes. So right when I got off of *The Bachelorette*, I was invited to go to a conference, a breast cancer conference, of all things, in Dallas. And I couldn't, for the life of me, understand why I was going to breast cancer conference. But a gentleman who's the CEO of LE&RN, which is the acronym for Lymphatic Education and Research

Network, their whole mission is to not only bring awareness to lymphedema and lymphatic diseases, but ultimately raise funds and change the curriculum and the research that will actually evoke change and hopefully someday start to see widespread cures and better accessibility. Ultimately accessibility to treatments for these patients, because it's a big concern, especially for Medicare patients. They have a lot of limits that they have to face to get access to seeing therapies, to getting garments, to getting pumps.

So I joined LE&RN after a dinner with Kathy Bates. She is Academy Award winning actress and she is a upper extremity lymphedema patient due to her breast cancer. And she has just been a great voice for bringing awareness to lymphedema and working closely with LE&RN.

And that's really what inspired me, because I think a lot of patients, when you have a condition that is not glorious, you know, you have the self-esteem part. And I wasn't ever really proud of my lymphedema. It's something I always kind of hid and was self-conscious about. But after being vulnerable and talking on a social platform like reality TV about my lymphedema, that's what really opened up this opportunity for me to use that celebrity, if you will, to just be vocal about lymphedema and encourage other patients and be that inspiration to them, that you don't have to let the lymphedema control your life. You can control the lymphedema and still have an amazing quality of life and go on to do great things despite the lymphedema.

So but it does, again, take daily discipline to manage that condition, because especially in states like Texas, Dr. Chapa, where it's really, really hot the vast majority of the year and humid, that tends to make the lymphedema flare up for a lot of patients. And even patients who don't have lymphedema, picture, you know, trying to take off your wedding ring in the summertime, it may be a little bit more challenging than, say, during the winter months. So when you have lymphedema, it becomes even more challenging in those summer months. So staying consistent and compliant with their compression ecosystem is very, very important to seeing successful patient outcomes.

Dr. Chapa:

You know, I think that's a great way to round out this discussion, because not only does it really change our, well for lack of a better word, stereotype, I guess, of what a lymphedema patient looks like or who it happens to, I think just understanding both the personal, the practical, and the medical side of this, was well worth it.

So I want to thank my guest, Cam Ayala, for joining me to discuss lymphedema and for his patient advocacy for this condition. Cam, great to have you on this program. And you're doing great things. Thank you for being our guest on this episode of *Clinician's Roundtable*. Any last words?

Mr. Ayala:

Well, conversations like this are fantastic. And so I encourage any of the physicians, nurse practitioners, therapists, or even patients alike who are listening, if you have questions, go to resources like lymphaticnetwork.org. Find out who in your local area is treating lymphedema. And there are answers, but it's up to you as the patient and as the physician to seek them

Dr. Chapa:

Fantastic, fantastic advice.

I'm Dr. Hector Chappel to access this and other episodes in our series, visit reachmd.com/cliniciansroundtable, where you can Be Part of the Knowledge. Thanks for listening.