

Elizabeth Ortiz, MD

In my world, definitely the most common autoimmune conditions I see are things like rheumatoid arthritis, lupus, psoriatic arthritis, and Sjogren's. The prevalence when you group everyone together is quite high and it does lean very heavily women more than men. These are conditions that tend to affect young adults. We think of them as affecting people who are kind of in their prime working years, so their 20s, 30s, and 40s. In some conditions, it's very strikingly more women than men.

Ellen Kelsay

That's Dr. Elizabeth Ortiz, a double board-certified rheumatologist and advocate for improved education, access and support to patients with autoimmune conditions. After completing her medical training at Cornell University, she began her rheumatology fellowship and journey as an educator at the University of Southern California. Most recently, Dr. Ortiz focused her expertise on designing a one-of-a-kind clinic, Connected Rheumatology, which utilizes a hybrid medical approach to provide holistic rheumatic care through telemedicine and house calls.

I'm Ellen Kelsay and this is the Business Group on Health podcast, conversations with experts on the most relevant health and well-being issues facing employers.

Today, Dr. Ortiz and I dive into the complexity of autoimmune diseases, conditions where the immune system mistakenly attacks healthy tissues affecting close to 50 million Americans and many more globally, 80% of whom are women.

Dr. Ortiz, welcome. We're thrilled to have you on with us today.

Elizabeth Ortiz, MD

Thank you. Thank you for having me.

Ellen Kelsay

I'm really interested to bring this conversation forward and learn more from you. As we were doing research, one stat that really stood out to me, and I'd like to start there, is that it's been estimated that anywhere between 24 and 50 million Americans, which in and of itself is quite a broad range, have an autoimmune disease. And that's a condition in which the immune system attacks our own tissues. A recent study published just a couple months ago in February of 2024 showed that as many as four out of five of those diagnosed are women. So, a very prevalent condition impacting women. We know in our work here at the Business Group on Health, a lot of focus has been on women's health issues recently, mainly though related to reproductive health and menopause, and not so much about autoimmune. So, really interested to shed some light on this for our audience today. We'd love to maybe just start with some of those rates that I just mentioned, the range of 24 to 50 million Americans, the prevalence of it being predominantly a condition that impacts females. So, help our listeners understand, like, what's behind those numbers? Why does it seem to be a condition impacting more women than men?

Elizabeth Ortiz, MD

I definitely appreciate the opportunity, because it is a women's health issue. You're right, it's actually much more prevalent than is immediately obvious. We have about 80 to 100 identified autoimmune disorders and they range across multiple specialties. I'm a rheumatologist. I specialize in autoimmunity and musculoskeletal disorders. But other specialists will also take care of different autoimmune conditions. So, gastroenterologists will take care of inflammatory bowel disorders, like ulcerative colitis and Crohn's disease. You have endocrinologists who take care of Hashimoto's and type 1 diabetes, and then neurologists take care of multiple sclerosis. In my world, definitely the most common autoimmune conditions I see are things like rheumatoid arthritis, lupus, psoriatic arthritis, and Sjogren's. The prevalence when you group everyone together is quite high. You're absolutely right, it does lean very heavily women more than men. These are conditions that tend to affect young adults. We think of them as affecting people who are kind of in their prime working years, so their 20s, 30s and 40s. In some conditions, it's very strikingly more women than men. So lupus, it can be 9 to 1, Sjogren's is 19 to 1 women to men. These conditions, not only do they affect young people, more women, but they also can affect a disproportionate

level of people of color. And so people of color not only have higher risk of developing these conditions, but when they do get them can also have more severe forms of the conditions.

Ellen Kelsay

Can you help us understand any research on why it does seem to be more prevalent in women?

Elizabeth Ortiz, MD

Yes, there's probably not one answer. It's likely multifactorial, which I've always thought is the medical way of saying we don't know. Hormones most likely play a role and kind of seem like the obvious first thing to focus on. We see a spike in the prevalence of autoimmune conditions around periods of time where women will have hormonal changes, so around pregnancy and menopause, but it's likely not the entire answer. A recent study that came out from a Stanford researcher earlier this year showed that there might be a link to women's extra X chromosome playing a role, specifically one of the proteins that's involved in turning off that extra X chromosome. I think we still have a lot to learn there. There's also some interesting information about how the microbiome might be playing a role because we know the microbiome in women and men are different. Then there's a whole other kind of world of research looking into the psychosocial factors that might be playing a role. It's likely not just one thing and I would even say it's probably not the same thing amongst different individuals. It's like a collection of triggers in the right individual that has the right gene then tips them over into autoimmunity.

Ellen Kelsay

Wow. That range of the 24 to 50 million, that speaks to the fact that it is really complicated. Many of these, as you said, there are 80 to 100 different conditions treated by different specialists, I imagine there are probably a lot of people that are living with some form of an autoimmune disease and it may not have been actually diagnosed yet. Would you posit that's correct?

Elizabeth Ortiz, MD

You have that number of 24 to 50 million, I wonder, well, how many of those are firm diagnosis? How many are unclear diagnosis? There's so much gray area. You also have the phenomenon of multiple autoimmune conditions. It's not uncommon for someone, for example, to have lupus combined with Hashimoto's, or to have rheumatoid arthritis, as well as Sjogren's. Why that happens, I've always thought of it as autoimmune begets autoimmune.

Ellen Kelsay

Also, as we were doing some research, it seems as though cases are on the rise. I wonder, are they actually on the rise or are more people aware and being diagnosed? Or is there something going on systemically that is actually leading to more conditions?

Elizabeth Ortiz, MD

We don't know exactly, but I would gather it's probably both. I think it's good that we're now having many more conversations about autoimmunity and just bringing it to everyone's mind. On the scientific and medical side of things, we are getting somewhat better at identifying cases earlier. So that's certainly going to lead to more cases being diagnosed. But there also seems to be other factors where we truly are just getting more cases, whether it be environmental or food related, all of that we still have to tease out.

Ellen Kelsay

You've already, I think, done a nice job of outlining what some of the challenges are. Sounds like there's research underway to better understand the X chromosome, the microbiome, the psychosocial factors. What else would you say are challenges in really understanding the world of autoimmune conditions that would lead to a diagnosis and/or the proper path of treatment?

Elizabeth Ortiz, MD

Gosh, there's so many challenges. I think one of the things, both from the provider and the patient's point of view, is the frustration that comes with how long it takes to finally get a diagnosis. Occasionally, you'll have someone who starts having symptoms and within a few months they have a diagnosis and a

treatment plan, but that's actually very rare. The more usual path is that someone can bounce around between lots of different doctors. They might be utilizing the emergency room. They might even be hospitalized. They're seeing all different kinds of specialists and not necessarily getting an answer. And, you know, you have to have an answer first before you can even then begin to think about a treatment plan. I think that that journey is not only frustrating because it can lead to a lot of suffering for the patient, but also very costly. I think one of the solutions to that is just educating as many people as possible about what to look for, what are the conditions, and how we go about thinking about them and diagnosing them, specifically to the providers we have on the first level of care that people usually come across - so your family doctors, your internist, PAs, NPs, ER docs, urgent care docs, these are the people that are going to see patients first. Rheumatology and autoimmune conditions in general is a confusing topic not only to the general public, but also to physicians and to people in health care. In a previous life, I did a lot of teaching and I worked in academics at a medical school. Rheumatology was seen as kind of this big black box specialty where you just had to memorize a bunch of autoantibodies. As a result of that, it oftentimes is not on the forefront of these doctors that see patients first. It's not always recognized that when someone needs to be referred to an autoimmune specialist or a rheumatologist. I think that really is a key component to get someone a diagnosis earlier so they can start treatment.

Ellen Kelsay

What are the treatment modalities? How do you as a clinician think about some of the current innovations and therapies that are emerging, whether it be CAR T or biosimilars? Let's talk about that landscape of treatment and how do you as a clinician think about that and how might a patient navigate that.

Elizabeth Ortiz, MD

Well, it really depends on the condition that we're talking about as far as how wide ranging our options are and how state of the art the options are. Because as much as biologics have, for example, changed the game when it comes to things like rheumatoid arthritis, we still are kind of close to square one when it comes to conditions like Sjogren's and scleroderma. We have what we call DMARDs, which are disease-modifying antirheumatic drugs that have been around for ages, you know, oral medications such as methotrexate and a bunch of others. Then we have the new biologics. In rheumatology, gosh, I think the number is close to 15, 16 different biologics that we have to choose from. Biosimilars are interesting. Just so everyone knows kind of what we're talking about, the FDA defines a biosimilar as a biologic product that's highly similar to a reference product, notwithstanding some minor differences. The FDA will approve a biosimilar if it's shown to have no clinically meaningful differences between the reference product in terms of safety, purity, and potency. There are a number of FDA approved biosimilars, not only in the United States, but around the world, and different countries have been using them successfully since as far back as 2012, maybe even before then. The thing to keep in mind, though, in the United States is that FDA approval is not the same thing as entry into the market for a number of reasons. Even though we have a very similar number of FDA approved biosimilars as other countries, the amount that we've been using them is much, much less. There's a number of reasons for that, you know, patents and different litigations that the nuances and details of is kind of beyond my understanding, but that's really one of the main reasons why we have as many that have entered the market. We also have low, or I'll say conservative, use by doctors and patients. I've said before, doctors are very conservative, they're slow to make changes, and patients tend to follow what their doctor says. There was a recent study that shows that in rheumatology, the use of the biosimilars for infliximab has grown, it's just growing slowly. Then you have the question of who's going to pay for it. The theory with biosimilars is that they're going to be cheaper, they'll drive competition, which will lower the price, and in the United States in particular, you know, our health system is such a uniquely complicated animal that how that plays out in our system, we'll see.

Ellen Kelsay

You made a really interesting comment when we chatted previously about the risk-reward scenario of CAR T treatments in autoimmune conditions relative to cancer, as an example. Can you expand on that a little bit more to help our audience think about how you as a clinician think about those types of treatments and some of the trade-offs and whether, quite honestly, they're worth it or not?

Elizabeth Ortiz, MD

Yes, definitely. I'm not sure if everyone knows what CAR T cell therapy is. This is really kind of an exciting new approach to cell-based conditions. What they're doing is we take the patient's own blood, we remove the T cells, which are a specific type of white blood cell, and we then infect those T cells with a virus that then has a genetic code that enables that T cell now to have a certain receptor that we want it to have. That receptor can be specifically built to target whatever cell we're trying to target. In the world of oncology, they've had really good success with this approach and it's a no brainer to then move that into autoimmunity, because B cells in autoimmune conditions are the cells that produce autoantibodies. Autoantibodies are the things we're always talking about in autoimmune conditions as if not causing the disease, being somehow intimately tied to the disease. The theory is, if we can create something that targets B cells, gets rid of them, you then will get rid of the autoantibodies and thus theoretically get rid of the autoimmune condition. This is what they've been doing or studying in autoimmune conditions and the results we've been getting have been pretty remarkable. It's small case studies and case reports, but they're taking very ill patients who have tried and failed multiple different therapies. They put them just through one round of this CAR T cell therapy. So far, these patients will have no signs of their autoimmune condition and what more is, they seem to tolerate it really well. When you start thinking about well, how can we take this and apply it to all of autoimmunity is when I as a rheumatologist start to get very cautious and kind of say, okay, well, we need to put on the brakes because as exciting as it is, we want to make sure that we are taking into account all the factors, not only their illness, but the severity of their illness, as well as the unknowns and the potential risks of whatever therapy we're looking to use. Then the CAR T cell therapy situation, we actually have the benefit of looking to our oncology colleagues because they've been using this, and they have more data on what some of those longer-term side effects may be, specifically this risk of a secondary malignancy. Now, so far, that seems to be rare, thankfully, but you have to take that into account when deciding when it's appropriate to expose a patient to that risk. If you have cancer or you have a very life-threatening autoimmune condition, the risk to take on the possibility of a secondary cancer might actually be worth it. But as you move down to less severe autoimmune conditions that are not life threatening, well, that's an equation that you have to think about and you have to really evaluate if the risk is worth it based on the severity of the condition. It's not to diminish anyone's experience with autoimmunity, because even if it's not life threatening, they are certainly life changing, but we don't want to just swap out one thing for another potentially worse thing.

Ellen Kelsay

Super helpful. Thank you so much. So a reason for optimism, but also cause to be somewhat cautious and as you said, tread lightly, depending on the severity of the condition and the patient's dynamics. All right, I want to shift gears a little bit. You mentioned earlier that, you know, the prevalence of younger patients being diagnosed with autoimmune being predominantly in their working years, 20s, 30s, 40s, 50s, women, people of color, how should an employer think about supporting patients that might work for them who have autoimmune conditions? What should they be aware of, things that they could be thinking about promoting or including in their health and benefit programs, how should an employer think about their workforce and autoimmune?

Elizabeth Ortiz, MD

Yes, I think a number of things. I think, first of all, just having easily accessible information about how to go about getting disability if a patient finds themselves in that situation, I think is important. I think also supporting alternative work arrangements. Autoimmune conditions as a whole can cause joint and muscle pain, fatigue and brain fog. All the symptoms can be exacerbated by stress, by loud noises and by bright lights, a lot of things that we find in a typical office environment. I think supporting alternative work arrangements, whether that means work from home or being able to take regular breaks or having standing desks, things like that can be very helpful. Also, I think having support and services that support patients in between their doctor visits can be very helpful. You know, we were just talking about the CAR T cell therapy and kind of how sexy and sophisticated that is, and it is, but I also think things that may be a little simpler, but can be just as impactful, especially when you start thinking about those non-life-threatening autoimmune conditions. The data supporting dietary and lifestyle interventions is really striking. I think being able to provide that, because unfortunately most of our doctor's offices are not able

to provide that, having some sort of service like that can be very helpful to support your autoimmune employees.

Ellen Kelsay

Obviously having access to the highest quality clinicians, focus on primary care, you know, all those things foundational to just a good benefit plan are also really critically important for folks that might be struggling.

Elizabeth Ortiz, MD

Of course. The primary care thing, I think, is an interesting thing that happens with autoimmune conditions. The idea and concept of a medical home is definitely the ideal, especially when it comes to managing chronic conditions, but there is a dynamic that ends up happening with the autoimmune patient that I'm not quite sure everyone understands that's not kind of lives this day in and day out. When you have an autoimmune condition, you tend to see your specialist more often than you see your primary care doctor. The problem with that is that your specialist is not a primary care doctor and their clinics are not set up to be medical homes. What can end up happening is things can actually fall through the cracks, even in a person who's actually seeing their doctor very frequently, because a specialist, just the way we think, is just very different than the way a primary care or family medicine doctor who has, you know, built a clinic to be someone's medical home thinks. I think not only letting patients know how important it is to continue to see their primary care, but have that be supported by their employer and the benefits that are offered, I think is really important.

Ellen Kelsay

You also mentioned, you know, stress as being a trigger. I would imagine in your practice, you see probably a lot of compounding issues related to quality of life and mental health. I'd love to hear more from you about nutrition, dietary factors and how you think about advising your patients when it comes to those considerations relative to their conditions.

Elizabeth Ortiz, MD

I think the first thing I do with patients is just bring it up. Oftentimes, people come to me and they're just thinking about their labs or they're thinking about their medications. I want to try to start to get them to think about a broader picture and how they live their life and how they eat, what they eat is a big part of that. I just bring it up and get them to start thinking about it. Usually the first question they have is, well, what should I be eating, what kind of plan, and what kind of diet should they be on? I tend to take a broader approach. Nutritional science is very varied as far as the results. You can find studies that show a keto diet is beneficial. You can find studies that show a vegan diet and then everything in between. Over and over again, the diets that have shown the most positive outcomes when it comes to quality of life, when it comes to disease, activity, is going to be an anti-inflammatory or Mediterranean diet, but how someone gets there is very personal. There are a lot of reasons people make the diet choices that they make and I try to help take small steps and first tell patients, listen, just observe what you're eating and observe how that makes you feel. I kind of give them some guideposts because 90% of patients with autoimmune conditions, when they eat a sugary meal, if they have red meat, if they have alcohol, sodas, they're going to have more pain and stiffness the next day, but I just really want them just to start paying attention. Then we can start, okay, that made you feel a certain way, let's see how you feel if we remove that. I also think it's really good if you're removing something, understand why the person's eating it in the first place, and if you need to incorporate something to take its place, it doesn't have to be food, maybe it needs to be an activity or something that's going to provide that person the same benefit they were getting from eating that particular food. You just kind of inch someone towards an anti-inflammatory diet.

Ellen Kelsay

So helpful. Thank you. We've covered so many really fascinating and really important considerations in this conversation. I always like to ask, and I think you've hit on some of these already, but as you look to the future, there's a lot of innovation, a lot more knowledge and awareness that continues to grow seemingly day by day about the prevalence and treatments for autoimmune conditions. What else gives you hope for the future or what else are you keeping your eye on as you look to the future as a clinician in this space?

Elizabeth Ortiz, MD

Oh, well, there's a lot. There's a lot to be hopeful about. I have always been excited when I see researchers taking what we clinicians see in the clinic day in and day out, taking that information and then looking deeper into it and trying to come up with why we're seeing what we're seeing and then produce some sort of standard of care that will ultimately improve the patient's lives. We oftentimes see how patients with autoimmune conditions are not sleeping very well and then that has now produced a ton of research looking into that and the connection between the immune system and sleep. We might find little nuggets that can help us go even further back and try to catch patients before they actually develop an autoimmune condition and we might be able to say, okay, you have certain sleep patterns that we know will affect your immune system and in certain individuals can lead to autoimmunity. So being able to catch that earlier, I think, is exciting. The other thing that I know is happening in lupus and I think it's happening in the other autoimmune conditions is being able to identify and diagnose patients earlier. We described that journey of people bouncing around and part of it is because of a lack of knowledge or understanding, but the other thing to understand is that the criteria that I use to diagnose patients with different conditions, they're not perfect. The criteria for some of these conditions relies on patients having either lab findings or physical exam findings that actually are indicative of an autoimmune condition that's gotten way out of control. We need to have a better way of identifying people earlier. That's with blood work, that's with genetic work. I think it'll be really interesting what comes out of the incorporation of AI to come up with algorithms and ways to identify people earlier based on family history. That, I think, is really exciting to me because if we can diagnose someone when they're seeing their second doctor as opposed to their fifth or sixth doctor, that will be really helpful and not only obviously help them with their symptoms, but just prevent a lot of downstream health problems that we know can happen.

Ellen Kelsay

Wow, Dr. Ortiz, there's so much to keep our eye on here. Clearly, it is a space that is evolving quickly. There's a ton of innovation, as you've just said, so many things to be optimistic about in the coming months and lots of research, as you said, being conducted. I'm just so immensely grateful for your time today and sharing your knowledge and expertise with our audience. I look forward to seeing what's next.

Elizabeth Ortiz, MD

Thank you for having me. This has been fun.

Ellen Kelsay

I've been speaking with Dr. Elizabeth Ortiz, a rheumatologist, on a mission to help patients with autoimmune disease learn more about how to understand and thrive with their condition. Amassing more than 4 million views on her educational YouTube channel, Connected Rheumatology, Dr. Ortiz has shared with us the biggest challenges of this disease class, how emerging therapies could help, and research on why autoimmune diseases more often affect women.

I'm Ellen Kelsay and this podcast is produced by Business Group on Health, with Connected Social Media. If you like this episode, please rate us and consider leaving a review.