

Redefining Health & Wellness

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Featured this episode: Shohreh Davoodi & Alejandra Spector

Shohreh Davoodi: Why, hello there friends. You are listening to episode number 21 of the Redefining Health & Wellness podcast. Before I tell you more about this week's guest, I wanted to invite you to participate in my annual holiday wellness challenge, Season of Self-Care. If you're listening to this episode in real time in November of 2019, I'll be enrolling people in my Season of Self-Care challenge through midnight on Saturday November 30th.

I've hesitated to even call this a challenge because it's different from most other challenges out there. Yes, there is a competition component, and you can win prizes, but the way you gain points is by taking actions to take good care of yourself during a time of year that can be busy and stressful.

I've run this challenge the last two years in a row, and the group we end up with is always so fun and so supportive of one another. This is honestly my favorite thing I get to facilitate every year. Plus, this challenge is 100% diet culture free. Each week of the three-week challenge you'll get new activities you can do for points across categories like movement and exercise, food and nutrition, self-care and mindset, and community and organization.

You'll get the chance to earn back your challenge entry fee, and win other prizes. If you're interested in learning more, or signing up, go to shohrehdavoodi.com/seasonofselfcare. That is, shohrehdavoodi.com/seasonofselfcare. And if you're listening to this episode post November of 2019, please disregard.

All right, now that that's out of the way, let me tell you a little more about today's guest, Alejandra Spector. Alejandra lives here in Austin, and is the co-host of the Latinx Mental Health Podcast. She's also living with an autoimmune disease called Rheumatoid Arthritis. Alejandra spoke with me about her experiences with RA, the messed up ways in which society looks at disability, defining having a life worth living for herself, and more.

To access the show notes and a full transcript of this episode, head to shohrehdavoodi.com/21. That's shohrehdavoodi.com/21.

[Music plays]

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Shohreh: Hey y'all, welcome to the Redefining Health & Wellness podcast, I'm your host, Shohreh Davoodi. I'm a certified intuitive eating counselor, and a certified personal trainer. I help people improve their relationships with exercise, food, and their bodies, so they can ditch diet culture for good, and do what feels right for them.

Through this podcast I want to give you the tools to redefine what health and wellness mean to you. By exposing myths and misconceptions, delving into all the areas of health that often get ignored, and reminding you that health and wellness are not moral obligations. Are you ready? Let's fuck some shit up.

Today on the podcast I have Alejandra Spector. She and I were actually connected through a mutual friend, and she has her own podcast here in Austin called the Latinx Mental Health Podcast. Alejandra, thank you so much for being here.

Alejandra: Yeah, thanks so much for having me. I'm excited to be interviewed.
[Laughs]

Shohreh: Yeah, I know, you're used to doing the interviewing, so it's fun to reverse roles, and be on the other side.

Alejandra: Mmhmm.

Shohreh: So, tell me a little bit more about you, and your podcast.

Alejandra: Yeah, so I always have like a hard time talking about myself, and like what it is I do. I think that the bio I sent you is a little bit vague. I live here in Austin, Texas. I'm a social worker by training. I've just graduated with my master's degree. I've worked in immigrant rights for eight years, on and off. And I've been co-hosting this podcast, the Latinx Mental Health Podcast for about a year, a year and a half. We're in our second season. Then that's sort of me in a nutshell.

Shohreh: Tell me more about the podcast itself, and what your goals were with creating that?

Alejandra: So, the Latinx Mental Health Podcast kind of, the idea came to me, at actually kind of a difficult point in my life, and in my health. And I wasn't

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really doing a whole lot, but I was listening to a lot of podcasts. And I'm like a big podcast junkie, and I listen to them all the time. And I listen to a lot of health podcasts. Like some mental health ones, health ones, I like history of medicine and science. But I was getting very frustrated because I wasn't hearing any stories of Latino people, like at all.

Or sometimes there would be one, but it was just like it's something I was missing, and I was wanting, and I was kind of in a point where I was having some difficulty. I wanted to hear my own experience sort of mirrored. And this was like in addition to all of the frustration I have about the media.

Any time you watch a movie or a show, the idea of what it means to be Latinx is very narrow, if we're represented at all. And so I called my friend, and now co-host, and co-producer, Ana Hernandez, and was sort of just like venting to her about how we should start our own podcast. And for me it was just kind of an offhanded remark, and she was like, "No, we should really do that."

And then we did it. Ana is like one of those types of people who is like when she gets an idea, and wants it to happen, it's going to happen. So, it really was just sort of, started off as an offhanded remark, an idea, and then we just kind of went from there. And here we are two seasons later.

Shohreh: Yeah, and I love that you noticed that there was this hole in what you were wanting to get out of podcasts. And collectively you guys decided you were going to fill it. That's amazing!

Alejandra: Yeah, I think it's, for most of my life, and I think a lot of people feel this way, it's like we have this idea that somebody else is going to do it, right? We get upset that there's something missing, and then it doesn't really occur to us that we can be the ones to make it happen. And that's been like a big lesson that I've taken away from doing this, like oh, if you want something, it's not always possible. But, it isn't always impossible either.

Shohreh: Yeah, I love that. Well, and you and I talked about before, when we were planning for this podcast episode, you had kind of mentioned to me this term, 'Latinx,' and how it's not that Latinx people are like this one monolithic group. And that was the first time I had really heard it explained that way, if you wouldn't mind expanding on it here.

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Alejandra:

Yeah, for sure. And I think that that's why I kind of wanted to speak a little bit more personally on your podcast, because I didn't want to speak for such a big group. I've been sitting down, and sort of trying to think about how to best describe it. And I think a good analogy would be the way we use the word 'queer.' You can say that somebody is queer, and you have an idea of what that means. But you don't know anything about that individual's experience right?

You don't have their background, and their history, and what their family is like. And it's just one marker of their identity. And I think that that's very similar to what it means to be Latinx, right? Like Latinx generally means a person of Latin American descent. So, Latin America being a region. So either the child of, or an immigrant, or somebody from there who probably speaks Spanish, maybe speaks Spanish, but all these other different languages as well.

So it doesn't even give you an idea of what language they speak. It says nothing about their race. Latin Americans can be white, they can be black, they can be Asian, any, just like anybody in the United States, right? Or anything about their cultural background, and religion. I'm Jewish. We don't think about Latinos as being Jewish, we think of them as being Catholic.

It's just another way of sort of lumping together a group, and sort of distancing them, I think, from whiteness, which is sort of the way I look at it, right? In the way that queerness is a way of sort of distancing folks from heteronormativity. And of course, with that, there's also the pride that comes of being part of that group right? Because I identify as Latina, but my experience isn't going to speak for everybody else's. Does that make sense?

Shohreh:

Yeah, I actually love that you use the analogy to queerness because as a queer person, that's near and dear to my heart, and you're absolutely right, myself and many, many other people use the word 'queer' to describe us. But I also identify specifically as bisexual, which is a very different experience from somebody who is gay, or somebody who is asexual, or even other bisexuals who have had different experiences than me. And you're right; I think in the US especially, we tend to use Latinx as kind of

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like a singular group, especially when we're talking about voting, and voting blocks.

Alejandra: Yes, voting, I mean media, I mean social work school, where we talk about cultural competency, which I think we could do a whole episode on that, and I'm not going to get on a rant about it [laughter] but there's some like issues about that, when we talk about Latinos, Latinx. We're talking about one thing, and it's just, that's not the reality.

Shohreh: Going back to what you said about how when we were originally talking about doing this episode, you know, again, because I knew about your podcast, I was like okay, what can we do about this that's specific to Latinx, whatever. And then you shared with me your personal story, and I was like, well, that's much more compelling to hear your personal story than, like you said, speak for a group. And we'll kind of switch gears to that now.

Alejandra: Okay.

Shohreh: So, you have Rheumatoid Arthritis, and you deal with chronic pain, and I would love you to share some of your experiences with the condition specifically, and then disability generally, if you'd like.

Alejandra: Sure, so, I'm kind of excited to be talking about RA, because people don't seem to know what it is. And maybe that's changing, but usually when I tell somebody I have Rheumatoid Arthritis, they're like, "Oh, my grandma has arthritis." I mean I guess your grandmother could have Rheumatoid Arthritis, but it's not necessarily that kind of arthritis.

And it's not 'just arthritis.' So Rheumatoid Arthritis is actually an autoimmune disease, and for those who don't know, generally what an autoimmune disease, it's your body, your immune system specifically, your immune system confusing healthy cells, and healthy parts of your body as a foreign invader. And so your body is basically attacking itself. And I won't get too technical about it, but basically in Rheumatoid Arthritis, there's something called synovial fluid, and it's all over. And that's what RA attacks.

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And so often the joints are affected and that's a way that a lot of people are diagnosed, and that's how I was diagnosed, because I started having joint pain, and arthritis. But it actually can affect your whole body. And so it can affect your skin, your eyes, your mouth, your lungs, your heart, your nervous system. You get flu-like symptoms and fatigue, along with chronic pain, and then the treatments are very aggressive, and that's kind of like the gold standard right now.

So, they say treat aggressively right away, so that there's not further damage, but the side-effects of those treatments can affect your liver, and your kidneys. And some of them have risks for cancer. So it really is much more than arthritis, and a pretty complicated disease, a complicated disease to sort of manage.

So, I'd worked in immigrant rights for a few years before deciding that I really wanted to go into social work school, to continue working with immigrants, but doing trauma work, and stuff. I applied to UT Austin, and I got in, I was really excited. In my first semester of grad school, and I had been feeling really run down and tired for a while. But I was also working a really, really stressful job. And I went to the doctor with all of these weird symptoms, and they would just be like, you're tired, or you're depressed.

And I was tired, and I think I was depressed, it was a very hard job. And so I kind of just, like what can you do? I just sort of went on, and I got into grad school. I started, and my left thumb had been swollen to double its size for a while. I was like, there's got to be something right, because if you're depressed your thumb doesn't swell. [Laughs]

Shohreh: Right, right.

Alejandra: But I wasn't finding anything. But finally I started going to an acupuncturist, and they said, "This looks like something autoimmune." So they actually, it was an acupuncturist who gave me a list of tests to ask for. And so finally was able to get in to a doctor. Finally got those results back, and this was in October of my first semester of grad school. And so I was 25, I was about to be 26, and I found out I had an autoimmune disease.

A few months later I finally was able to get into a rheumatologist, and I was diagnosed with Rheumatoid Arthritis, and it was pretty devastating news. I

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didn't really know what it was either, at first, and then I started Googling, which is just like, don't do!

Shohreh: A dangerous path to go down.

Alejandra: Yeah, and everybody says that - you're gonna Google, but just know that often you'll see the worst case scenario. So, yeah, so I was diagnosed. It was very painful. I was told that I should go on methotrexate. In big doses it's a chemo drug, in low doses it's used to treat your immune system, but I was too afraid to go on it because I had heard all of these things about it. So I resisted treatment for a while, and then I just got sicker, and I was getting to a point where I really couldn't dress myself. I was having a hard time walking.

Like it was literally eating at my joints, I have lost bone in my hand because of RA. Yeah, I mean honestly, something I don't talk about too frequently, and don't want to give too many details too, but I basically had a nervous breakdown after that. And finally went on different medications for it, and yeah, they're kind of a bitch to be on. But I can walk, so it's been sort of a process of coming to accept that I have this thing that's never going to leave, to try and be okay with that.

Shohreh: Yeah, I think with autoimmune disease, that's one of, honestly, the hardest things is when you get your diagnosis, it's like, cool, this is a life changing thing that isn't going anywhere, right?

Alejandra: Yeah.

Shohreh: You now know that you have this, and you have it forever, and all you can do is work with it, and try to manage it to the best of your ability.

Alejandra: Well, yeah, and talk about wellness culture, you know, everybody sort of tells you or I mean, wellness culture tells you that it is your body, and that you fix it if you just eat right, and do all the lifestyle things. And I did, I tried everything, and I don't want to trigger anybody, or details of what it was that I did, but it didn't help. And it just made me insane. But there's that pushback too, that's really, really unhelpful, and I think a lot of people when they're first diagnosed, and maybe throughout the length of their illness, have to deal with that.

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I don't stand for it anymore; I don't let people tell me, like give me any advice [laughs], almost, maybe to my detriment anymore. But I think it's a pushback against some of that.

Shohreh: I think that's so common. I see that a lot with people who, you know, they have a good intention when they're like, hey, have you tried... But, I always tell people, I'm like, if you're tempted to say that sentence, just shut it down.

Alejandra: Yeah, that's great advice!

Shohreh: The chances of you having the miracle cure for the person you're talking to, are like one in a bajillion. You don't have it. They've probably heard that advice before, and they didn't ask for it, so why are you giving it?

Alejandra: Yeah, and they've already tried it, probably too.

Shohreh: Right.

Alejandra: And I actually, like I did at the time, since I was still in grad school, I had access to all the databases. I went into all of the academic databases, and looked up lifestyle stuff for RA, and diet. And found one article, and it said that fasting helped, but as soon as you started eating again, the effects would be undone. So they were like, so we don't recommend it, because you need to eat to live! [Laughs]

Shohreh: Well, I'm really glad that was that the bottom line of that article! [Laughter]

Alejandra: Yeah, so it was like, we can't recommend fasting, if there's no benefit, like once you stop fasting, because you can't fast forever, you will die.

Shohreh: Oh god. [Laughter]

Alejandra: So yeah. Don't try that!

Shohreh: Yeah, don't try that at home! I am curious how RA, and disability in general have affected your body image. Because you've mentioned this idea that essentially RA, it's your body attacking itself, right?

Alejandra: Yeah.

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Shohreh: And I just have to think that could do a number on a person's body image.

Alejandra: Oh yeah, oh boy, that's a good question [laughs]. I struggled with an eating disorder for a long time, pre-diagnosis. And it's something that I've sought treatment for, and continue to seek treatment for, now. And I think it has been a complicating factor in full recovery. I think the treatment world has gotten better about it, but there's a lot of talk about, what is it that your body can do for you?

And people don't say that as much as they used to, which is great, because it used to really bother me, because I was like, well, my body can attack itself! [Laughs] It can eat itself! So yeah, and eating disorders are a lot about control right? Trying to control your body. So what if you already kind of struggled with that, and all of a sudden you have a body that is so out of control?

And I did try to control it with food. It kind of sent me down not a very nice path for a while because I did take in a lot of those messages, and I thought I could control it. And if you have a history with an eating disorder, you should never go on an elimination diet. Like just don't ever fucking do it anyway! But that was what I was being told would maybe help.

And so now, it's still a struggle. I still get frustrated because I can't move my body the way I could move it before either. Yeah, I think it's just one of those like work in progress. And I think, if I were to speak to treatment professionals, I would say that that's something that we really need to talk about more, and work on when dealing with folks with disabilities, and eating disorders. Because there is so much emphasis on the body, and I can understand that, but how do we help folks who are sick?

Who aren't going to find health, even after you get better, right? The sense I get is that a lot of motivation can come from that, wanting to be healthy, and missing health, or wanting health, and being told that you're going to get healthy. And I think that that's a lot of the language still, like in recovery. Okay, what if you're not going to, and what if your body is still gonna hurt, and what if you're still gonna be tired?

And what if you're actually going to be more in your body in some ways, because you're not numb from your eating disorder? It's tough.

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Shohreh: Yeah, I think in the same way that for some people it's really helpful to think about what their body can do. For other people, that's just not gonna work. For some people it's helpful to think about health, and again, maybe expanding this idea of health, and for other people it's like, that's not going to be the thing. So, it's really about having, I think, a variety of different tools, and an understanding that there's no one-size-fits-all in this treatment, right?

Alejandra: Yeah.

Shohreh: You really need to be aware of an individual's background, and experiences, and abilities, before you can give them any suggestions or any ideas. And if all the language is the same, that's going to leave people out, and they're going to feel like they can't have that treatment, which is not what we want.

Alejandra: Yeah, and I think for me, and this is something that is talked about a lot in dialectical behavior therapy, it's this idea of the life worth living. For me, I think that's been the most helpful tool, and motivator. Oh, I'm doing this because I want to have a life, right? Like I want to have a life that is worth living, and I want to have all of these experiences as a human. But it took me time as a person with a disability to learn that that was even possible for me.

And I think that took too long, and it's not, I'm not blaming that on professionals, or anybody, saying that that was just something that happened, right? I think partially because of the way treatment is done, and partially because of our sick society. And partially like my own internalized ableism, right? It took me a long time to even get to a point where I could say, "I, as a person with an illness, can have a life worth living."

And once I've accepted that, my motivation has increased. So I think we need to tell people that they can have a life worth living, and I think we need to focus on it more, because it's a really nice concept, that I think sometimes gets lost in all of the... You know, eating disorder recovery is really complicated, and god bless those treatment providers who are doing the work, because it's not easy.

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Shohreh: Yeah, but I agree. I think that is something that's important to emphasize, whether working in eating disorders, or what I do with disordered eating, and intuitive eating, and all these different things. At the end of the day, it's still about this redefining, which is what this whole podcast is about. I'm purposefully talking about redefining health and wellness here, but obviously life is a part of that too. Like what is a life worth living? And you have to define that for yourself. I think that's hurdle number one, because if you listen to what society says about what is a life worth living, that's super narrow, and it leaves out a lot of people.

Alejandra: Yeah, yeah.

Shohreh: I know that you mentioned to me that you've kind of largely been unable to work due to RA. Has that been a struggle for you in a deeply capitalist society that so strongly emphasizes work as being our worth?

Alejandra: Oh yeah, for sure. And largely I've worked, I haven't been able to work in the way that we're supposed to work, I guess. So maybe that's, I don't know if that's like underemployment. It took me five years to do a two year program for grad school because of RA, and just the complicating factors, and having to take breaks, and stuff. And it would be a complete lie to say that it hasn't affected my self-esteem and my view of myself.

As much as I have always been, and I'm the child of activists, lefties, through and through, and still those messages have deeply impacted me in the way I view myself. And it's also, I think, really hard because not only are you not making the sort of money you think you should be making, or enough money to support yourself. I mean that's the bottom line. Medical care is extremely expensive, and it's like you're just hemorrhaging money, and you're not bringing anything in.

And so you can feel like a burden to those people around you because it's either you're taking out loans or somebody else is footing the bill. And that can be really painful. But I guess I wanted to share this moment I had with my mom, if you don't mind?

Shohreh: Of course.

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Alejandra: It was kind of eye-opening for me. It didn't magically make it all better, but it was sort of like one of those moments. A few years ago I had to go in for some pretty extensive treatment and as inpatient for a while, and it was very expensive, and my parents paid for it, and I felt so bad. And I saw the bill, and I had had over the upcoming weeks, like several conversations with my mother where I was just like crying, and apologizing.

I was so sorry for being a burden, that I didn't know if I would be able to take care of them when they were older, and now they're using their money on me. And my mother started crying, and she said, "Alejandra, what is it that I've done to make you feel like a burden? You're my child, and we can do this for you, and we want to do this for you. And when you tell me that you're a burden, I feel like I've done something wrong as a mother."

And it was that sort of moment when I realized that, well one, I never said, I never used that word with her again, and two, I realized that I had reduced myself to a dollar sign. That my worth was based on how much money they were spending on me, and not the fact I'm somebody who matters to them, and I'm somebody that matters to a lot of people. And I have a life that is valuable and worth living, and it has nothing to do with how much I'm costing.

They just wanted me to be alive because they want me. And that's hard to remember when you're being pelted with pills, and can't do the 40 hour week.

Shohreh: I think it's hard to remember too in a society that emphasizes that people who have disabilities, don't have as much to contribute -

Alejandra: For sure.

Shohreh: And can't be as much a part of society, and that's just fundamentally not true. It's just we have this very limited viewpoint of health being part of worth.

Alejandra: Exactly. You know, I was thinking about this the other day, and I was frustrated. Who knows, I was frustrated about something, but I was thinking about how subversive disability is in some ways. It's not like you

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choose it, right? You don't choose to get sick, but when you do, you're sort of saying like, this system doesn't work. And I can't be a part of this system, and when you start sort of analyzing why is it that I can't be a part of this system, you realize that it really doesn't work for anybody.

And that if we were to create systems that actually cared about people, and actually took individuals into account, then everybody would do better. And I think people with disability get punished for that, on some level, for not being able to like play the game. For saying, this doesn't work.

Shohreh: I think you especially see that in inspiration porn, of people with disabilities.

Alejandra: Oh, thank you for saying that!

Shohreh: Yeah, like that's what that brings up for me. So inspiration porn is like, these are the videos that you always see on social media, where it's like a person who is competing in the Paralympics, it's usually someone with a disability is doing some sort of physical feat of strength, or ability. And then you have these captions that are like, 'What's your excuse?' 'If they can do it, you can do it!' I'm like, oh my God, this is so terrible.

Alejandra: Yes, I hate that so much! I actually got into a fight with somebody about it not too long ago. [Laughs] Did not agree with me, but everybody is allowed to disagree, even though I feel like I'm generally right. [Laughter] No, for sure, I think what we do is reduce somebody to their ability, to one aspect of their identity. Because we don't fucking know what that guy's life is like, the Paralympic. Like he could have a great life. He has all of the support, maybe all of this money for training. A wonderful family, and support system. We don't know.

Like disability is a hard thing that happens to people, but so is breaking up. It's like just one hard thing that can happen to you as a person, and it doesn't necessarily have to determine the whole trajectory of your life or whether or not you can or won't do something.

Shohreh: Yeah, because there's this dichotomy where we basically, as a society, put people with disability into two categories, right? You're either in this

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inspiration porn category where it's like, you're doing the best with what you can, you're doing amazing. Or we have the like, you're tragic side of it.

Alejandra: Yeah, it's not fair, right? Like I think we need to give people with disabilities permission to just be human, and to just have bad days sometimes, and to be resentful of what's going on in their life, just like anybody else, right? We all have bad days with bad attitudes, and it says nothing about our entire life. I get really upset when somebody says to me, "You're so brave," or, "I could never do what you do," because it just feels like a way of distancing themselves from something that is such a human experience, that can actually happen to anybody.

I wasn't born disabled. Illness is just such a normal part of life that we pretend isn't. Disability is just such a common experience that we pretend isn't. And I don't know, I don't want to get too nihilistic or too existential, and so stop me if I am...

Shohreh: I'm all about existential dread.

Alejandra: Okay, great, because I'm going to start talking about death. I think at its core, it is this fear of death that distances folks from folks with disability, or at least folks with illness right? When somebody says to you, "You're so brave," or somebody says, "I could never do this," you're saying you don't want to do this. You're saying you don't want to look at it. It's so much easier to just sort of brush it off as somebody being extraordinary, when really they're just coping with something that we're all going to have to cope with in one way or another, at some point.

Our bodies deteriorate, and fall apart. We lose ability, and we die. And my condition isn't that terminal, other than, well, I'm a human, and so that condition is terminal. But, I think when you are diagnosed with an illness, I think you're diagnosed young, and you have to deal with it on a daily basis. And I have to deal with it on a daily/hourly basis. Like I spend a lot of time tending to my own body.

You kind of realize how ephemeral it is, how tenuous our existence is, how delicate and fragile we are. And how it can all sort of be taken away, and that's hard, and it's a gift, and I don't think lots of people want to talk about it.

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Shohreh: And I think this also dovetails in with the wellness culture in general, right?

Alejandra: Yes.

Shohreh: Because I think people are using wellness culture as a way to attempt to outrun death, right? They're like, if I just do this thing, and this thing, and this thing, I'm going to live way longer, I'm going to be healthy forever, whatever. And it's like, maybe you will.

Alejandra: Yeah.

Shohreh: Maybe you won't. Like you don't have as much control over that as you think you do.

Alejandra: And that's the thing with illness, right? Like that's the thing with disability, it's like this reminder that you have so little control. That we are all at the mercy of our own bodies, and once it starts going south, there's not always a whole lot you can do other than what anybody would do, which is, we all just keep living, right? Like when you say I'm brave, or when you say you couldn't do it, the thing is, you could do it, and you would do it.

Shohreh: Yes, exactly, like that's a special kind of bullshit, because it's like, we're all going to do what it takes to survive. If you receive a diagnosis tomorrow, you're going to do the exact same thing.

Alejandra: Yeah, you're going to have really bad days, and you're going to be like pissy about it. You can ask my friends, some days I'm like a grumpy old man, and like other days, I'm very Zen, and like, oh yes, I've born so many gifts from being sick. But you know [laughs], that's not every day.

Shohreh: You mentioned the cost of your medical bills, and kind of working with your parents on paying for those. I feel like having a disability in the U.S. is obviously further complicated by our very shitty, for-profit healthcare system, which I want to hear your thoughts on public health matters as well. Because obviously it's a huge problem if you have a disability.

Alejandra: For sure. I have loads of thoughts. I think one; I've been following your friend, Maegan. Her story, and I really enjoyed her episode.

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Shohreh: For those who don't remember, she was on one of the first couple of episodes, I'll link to it in the show notes, talking about her ovarian cancer, and how she was diagnosed with it a second time after being misdiagnosed for almost a year.

Alejandra: Yeah, so I was reading the update today, and just seeing about how she couldn't get onto long-term disability, and that just broke my heart. Because in other countries this wouldn't be an issue right? When you're sick, you don't need to be stressing out about this stuff. Like that's just going to make it all worse. And it isn't something that has to happen in this country, but there is enough money to provide people with the healthcare that they need to get better.

And to ultimately be more productive. If that's how we're measuring success, which I don't like to, that's awful. I've got a little bit off track there.

Shohreh: No, that's okay. [Laughter]

Alejandra: I feel that I'm kind of at this point in my life where I'm starting to get back on my feet, and I'm having to spend a lot of time taking care of myself. And it is that taking care of myself that is allowing me to get back on my feet, right? So I'm not saying that health behavior does not help right? But the only reason that I'm able to do these behaviors, is because I have the basics. For me, it's my family that's supporting me, and I have like a big family, a big extended family, and lots of, not only financial, but emotional, and social support.

And it's having those basics, like knowing that whatever happens, I'm not going to be out on the street. I can afford my medication. I have clean water, and food, and just all of those like, Maslow's Hierarchy of Needs, all of those basics covered, and at that point, that's when you can start really taking care of yourself.

And once you can start taking care of yourself, you can give back to others, right? You can have that sort of, that life that you want. You can have a life, even with a condition. You cannot have that life if your basics aren't being met. And not everybody has the familial support to do that, right? And even if they have the emotional and the social support, not

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everybody's family has the money to cover the costs, or to make sure that that person is able to stay in housing.

And so then what ends up happening is that people's lives aren't realized because they don't have their basics. And it's with anything, right?

Anybody, but I think especially if you have an illness, because you have that much more to deal with in order to be okay. It takes so much more, and if you don't have the basics, then you're not going to have a life. And people in this country get so worked up when you talk about benefits of any sort.

I don't understand it at all. Why do people get so upset when you talk about using disability, and why do people get so upset when you see a disabled person having fun? Maybe I'm more sensitive to it now, but people saying things like, "Well, if they can have a day out, then why can't they work?" Well, that's just not how it works, you know?

Shohreh: Right.

Alejandra: If you really care about people's health, because we have a lot of people who say they do right? Very, very worried about it on the internet, about what people are putting in their mouths. If you really care about people's health, then you'll care about housing. You'll care about Medicare for all; you'll care about clean water, and reparations. And all of these societal, systemic things that can allow for somebody to have even a fighting chance, to have any sort of life.

Shohreh: Yeah, because as we've talked about on the podcast before, many times, the social determinants of health matter so much more than anything that we can do as individuals. And speaking of health, so obviously a big part of this podcast is about defining, or should I say redefining health and wellness for ourselves. I'm going to combine two things together here, because you've listened to the podcast, so you know that at the end I always ask: How do you define health and wellness for yourself, at this moment?

And so I do want to hear your answer to that, and in addition, I wanna talk about how there's this very narrow view of health as being essentially an absence of disease or disability. And where that leaves people then, who

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are struggling with disease or disability, to define health for themselves? Does that just mean that they accept themselves as forever 'unhealthy,' or yeah, I'd like to hear your thoughts.

Alejandra:

Yeah, I have been thinking about this a lot, and partially in preparing for this interview, but also just because it is something I think about a lot. What does it mean to be healthy when health is never going to be on the table, right? There is no cure for RA, as of yet. There might be at some point, but there isn't right now. And I think one of the things that comes to mind is that, I think one of the beauties of sort of like, perhaps disability rights, or the Disability Rights Movement, and the Health At Every Size movement, and fat liberation, is that you get to really define that for yourself.

That's what's empowering, right? Like you get to decide what it means for you to be healthy, because if you look at the medical model, and I'm enmeshed in the medical model. I go to five to six appointments weekly, at the least, and I'm on all of these exams and a human pin cushion at this point. I spend a lot of time with doctors. And they have a way of making you feel really small, and really dehumanized.

And just like you're sort of the numbers, right? Like if your numbers are up to a certain level, then you're good, if they're not, it's bad. If your scan looks a certain way it's good. But they don't ever sit down and ask you, "So how is your soul doing? Are you doing things that matter to you? Are you living a life worth living? What is getting you out of bed in the morning?"

I just get asked, "How long is it taking you to get out of bed," because your joint pain you know? Nobody ever asks me what my motivation is, and that's the whole thing with the medical model, too. We act as if like, a person's body isn't just a sum of its parts, which is the frustrating part of dealing with an autoimmune disease that affects your whole body. It's that you just end up getting passed around, right?

You become a number. You become a code. You stop being a human. So, I think if you look at health that way, well, then you're gonna lose, if you have an illness, then yeah, you're never going to be healthy, you're never going to be okay. Because you're never going to have the numbers that

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you need to have. But, if you sit down and ask yourself, well, what does it mean for me to have a good life? I think that's where we have some control.

And I use the word 'control' cautiously because there's, again, like we were talking about all these social determinants. We can't always control those things, but assuming that you have what you need, right? Then you can ask yourself, okay, what does my life need to look like for me to feel that it's worth it? I think is how I look at it.

And so health for me, at this moment, because I think that definition can change, and that's the beauty in it, right? I can decide at another point that this is not how I'm going to measure health, but health for me is being able to sort of like look at my whole situation, and see the good, and the bad, and the hard, and the beautiful. When you have an illness, it's very easy to kind of go into this place of self-pity right? Because everybody is telling you that it's hard.

And you can get really self-involved because you're having to spend so much time with your own body, and attending to it. You can kind of get this self-absorption, this sadness, this like deep darkness around you. And that's valid, and I think there's a time, and a place for that, because it is hard right? And nobody is saying it isn't hard, but there's no situation in life that is completely bad, and that there are lessons that can be learned from each situation, right?

And so at least for me, one of the lessons I've learned is how to look at time differently. How to spend my time. Time is not money, right? Time is time. Time is meant to be spent here, now. That is a lesson that illness teaches you. And there are other ones, but I won't get into it for the sake of [laughter] brevity, because I'm going off, metaphysical or something. But if I can take that, right, I can take all of that, and then I can use it to do something. To make something, to give something of myself.

If I can do those two things, then I think that's the healthiest I am. And you know, sometimes I can see all the gifts, and I'm so depleted that there's not a whole lot I can give. Sometimes I can't do either, and sometimes I can do both. And when I can do both, it's beautiful, and amazing, and it

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feels really good, and it doesn't matter if I'm healthy or not because I'm giving of myself. I'm doing something with my life.

And I don't have to make money doing that thing. It would be nice [laughter], you know, please hire me; I would love to make some money! But, it's also like, not going to determine whether or not I'm okay.

Shohreh: I love everything that you said. I especially love this idea of health being measured in life because I don't think anyone on the show has quite described it in that way before. But it's something that I think about a lot. At what point does the pursuit of trying to live take away from living your life, right?

Alejandra: Exactly, exactly, and I think, yeah, you probably see this a lot with the work that you do, and how stressed out people, how stressed out healthy people get about their health, which blows my mind!

Shohreh: Yeah.

Alejandra: [Laughs] Yeah, it can become its own thing. Somebody once told me that health is a tool, and it isn't a moral obligation, it's a tool that can be used. And so if you have it, use it.

Shohreh: I actually think that's a great way to describe health, because exactly, it's like if you don't have the tool, that doesn't mean you don't have other tools.

Alejandra: Exactly.

Shohreh: It doesn't mean that you are shit out of luck, right? Like you have other things that you can bring value to your own life, and the lives of others, whether or not you are healthy. And I think in general this idea that we need to be healthy to be good, virtuous people is obviously ablest as fuck, so.

Alejandra: Yeah, it's just not true.

Shohreh: Exactly.

Alejandra: And I think if we really listen to disabled folks more, we gave more of a platform, and more space, we'd all be so much better for it.

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- Shohreh:** Yes, I think that's so important in general. I think we have a lot of assumptions about disability in society, and again, we have a lot of this inspiration porn, and these other things that are giving us this viewpoint of disability. And it's like, go talk to, and learn from disabled folks.
- Alejandra:** Yeah.
- Shohreh:** That is the best thing you can do for anybody, is hear those stories. Hear from actual people. Hear their preferences about how they want to be treated instead of just assuming.
- Alejandra:** Yeah, and don't just assume everybody is angel too. There are some disabled assholes. I would just like to say that!
- Shohreh:** There are assholes of every flavor in the world [laughter].
- Alejandra:** Yes, I just hate this idea that somehow if you're disabled, you like reached the mountain top [laughter] for life, and are good and pure. Like, no, just not true.
- Shohreh:** Not quite! [Laughter]
- Alejandra:** Yeah.
- Shohreh:** Thank you so much for being here Alejandra. This was a really great conversation. I think this is gonna be super impactful for my listeners. How can people find you if they would like to keep up with you?
- Alejandra:** You can't find anywhere! I mean you can look up my name, I'm like the only person with my name, I have a weird name. But you can find the Latinx Podcast at Instagram, our handle is @latinxmhpod. You can find us online at, yes it is, www.latinxmhpodcast.com. And I think we're on Twitter, but we don't really use it, and then you can find us on Facebook, by just typing in the Latinx Mental Health Podcast. And if you just message us through there, I'll talk to you. [Laughter] Maybe...
- Shohreh:** Like, no, no, I don't want to talk to my fans.
- Alejandra:** Somebody will talk to you! [Laughter] No, we will talk to you

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Shohreh: Fantastic. Thank you so much for taking time out of your very busy schedule.

Alejandra: Yeah, no, thanks. I really enjoy listening to this podcast. I'm excited.

Shohreh: I'm so glad that you've enjoyed listening to it, and now you get to be one of the people on it, super cool!

Alejandra: I know, I know, my first time on somebody else's podcast. [Laughter] You broke my cherry! Oh is that weird? [laughter]

[Music plays]

Shohreh: And that's our show for today. I appreciate you listening to and supporting the Redefining Health & Wellness podcast. If you enjoyed this episode, it would mean so much to me if you would subscribe, and leave a review with your podcast provider of choice. It will really help other people who might benefit from the podcast to find it more easily.

I also love chatting with listeners, so feel free to screen shot from your podcast player. Post on social media, and tag me. And if you're looking for more information on what I'm all about, and how to work with me, head on over to shohrehdavoodi.com. I hope to see you for the next episode.