Treating Heart Failure in Adults with Congenital Heart Disease: Mental Health Concerns and Treatment

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

Dr. Burchill: Welcome back to Interview With The Experts, a podcast series from Mayo Clinic, Cardiovascular Education. I am your host, Dr. Luke Burchill and I lead heart failure care for adults with congenital heart disease here at Mayo Clinic. Joining me today is Dr. Laura Suarez Pardo, a consultant psychiatrist who here at Mayo Clinic, who I have had the great fortune of collaborating with, and we're seeing patients both in the adult congenital clinic but also in our psycho cardiology clinic. And Dr. Suarez Pardo is my partner there, providing care so that we're addressing hearts and minds for the patients that we see. Welcome.

Dr. Suarez Pardo: Yeah, thank you so much for having me. It's a pleasure to be here and collaborating on this important work.

Dr. Burchill: And so, you know, I've seen this in my practice and I'm seeing it more and more of patients coming in, with mental health needs, mental health concerns. I thought that we might start with a really simple question of, what is the difference between mental health and mental illness?

Dr. Suarez Pardo: Yeah, that's actually a very important thing to consider. So when we think about mental illness, it's really those kind of conditions or disorders that affects one's ability to think, feel or behave in a way that impacts their functionality and their ability to complete and do their day-to-day tasks. When we think about mental illness we think about an anxiety disorder, a depressive disorder, psychosis, bipolar disorder. Now when we think about mental health, it's more our emotional psychological wellbeing that impacts how we make decisions, we problem solve, we relate to others, we accomplish our, you know, daily tasks. So that's kind of the main difference. And it is important, I would start with mental health. I think it's a key part of, you know life and kind of making us be able to adjust to problems as well as to adjust to our work, our home environments. If mental health deteriorates, then they'd catch transition to mental illness.

Dr. Burchill: And so when I'm seeing patients and people come in with all sorts of life stresses, I'm really needing to think about, okay this might be quite a normal adjustment to some pretty challenging circumstances, but the question that I have to answer in my mind is, how is this impacting the patient's function? Is that, I'm I simplifying things too much?

Dr. Suarez Pardo: I think that's actually pretty accurate how it is impacting their function and how it is impacting their ability to recover and follow your guidance. So I think those are the two things but certainly function is the key word.

Dr. Burchill: And I know we're not getting into a playbook for how do you do a psychiatric or mental health assessment but what sort of questions do you find useful for really understanding

whether someone is rising to the challenge and able to function versus not? What would you recommend for people listening today?

Dr. Suarez Pardo: Yeah, I think the first thing that's important is to open a safe space for listening. Oftentimes we're pretty quick at asking questions or like wanting to really do, right? We in a way are fixers, we wanna fix but I think it's opening a safe space where people can just sort of, tell us what's going on. And when people struggle, they struggle and share that in different ways. Could be through pain, could be through physical symptoms could be through tears, fighting with us, right? They might get angry, right? At us. And all of that just has to be a sign that we need to play pause, open a space, listen and ask, what's going on? Now we think about function I think, when people are unable to really follow appointments, recommendations, when they are not able to take their medications, when you're losing track of them from a medical perspective or home, you know, you have a caregiver who says, boy we're not able to get this person to do that or to socialize when they isolate, when work gets them in trouble, so if they go to work now they're not doing as well as they used to, maybe fighting more with children. So all of the aspects of life when that becomes impacted is when it kind of like a red flag that something is going on.

Dr. Burchill: I really like that because I think that sometimes that social history component of a cardiac assessment I think it might be shrinking over time. And in some ways in this world that we're living in now, it probably needs to expand again. And I completely agree, just taking that step back and giving some space for people to tell you more broadly about, you know, the experience of their life, is so helpful for for understanding where they're at.

Dr. Suarez Pardo: Yeah, and I will add that, you know, heart is very important, but heart comes with a human, who comes with a context and that context is social and it has all other pieces that we cannot forget. So we might fix the heart, but that's not all of it. And fixing the heart requires other things, right? So...

Dr. Burchill: That's right. Yeah, I like to say to my patients that the heart is within a body, which is within a person and a soul and a context and a culture and a society.

Dr. Suarez Pardo: Yeah, exactly.

Dr. Burchill: You and I know that's why we have so many great conversations, I think that we share some beliefs there. Let's switch track a bit and talk about, what are the common psychiatric or mental health diagnoses that we see in our adults with congenital heart disease? And maybe while you're at it, you know, why are they at greater risk for these conditions?

Dr. Suarez Pardo: So, you know, anxiety and depressive disorders both are really highly recognized, significantly higher than a general population will have. And the third one that's really important is traumatic distress, and even post-traumatic stress disorder, I'm gonna leave that one last. But if we think about depression and anxiety, there's lots of things. So if we think about a child, you know growing up with a chronic illness there's lots of things that it's different, right? So even the attachment to the parents is different. The parenting style is gonna be different. Their ability to independently manage, you know their health, the difficult healthcare

systems that we have the autonomy to communicate and be assertive about what they need, all of that really starts getting lost. And as they grow, I think that really builds into uncertainty. So what we've learned is that uncertainty about, you know, illness, about job stability, about fertility for women, right? All of that really increases psychological distress and increases the risk of these patients to develop anxiety and depressive disorders. Not to say that they have to keep up with us, right? They have to come to our appointments, they have to take medications, they have to count their bodies for symptoms and tell us when they need us, they have to go through surgery. So all of that really makes it difficult and each and one of us copes and adjusts to illness differently. And the burden is sensed differently also based on the context, right? So if social support is not as strong, or if you have difficulties with your partner or your parents, you know, all of that is gonna play into how you adjust to an illness making increased risk.

Dr. Burchill: And I've seen in some studies, we're looking at anxiety and depression as being 20, 30% of the patients that we're seeing, may have a diagnosis of anxiety or depression.

Dr. Suarez Pardo: Yes, correct, it's around 20 to 30%. Now, if we think about even questionnaires just for screening or asking for anxiety and depressive symptoms, not a disorder, it can be up to 40, 50% of positive symptoms.

Dr. Burchill: Right, so you are talking there about like the general anxiety scales or the PHQ-9,

Dr. Suarez Pardo: Correct.

Dr. Burchill: PHQ-9 and the short form version of those. So, okay I mean, lots of my patients come in and they report symptoms that sound like anxiety or they report symptoms that sound like they've got some low mood. Again, would you say that it's keeping a focus on, yeah, they've got some symptoms but how is it impacting their lives and their ability to rise to the challenge of their sort of daily, you know, needs?

Dr. Suarez Pardo: Yes, exactly. And anxiety specifically, I'll mention that, because anxiety is a normal feeling right? To to a degree we all, have some anxiety to get out of bed and get to work and do all of our daily tasks. But it's really the question, when is anxiety getting in the way of you doing your things, right? When is anxiety or depressive symptoms taking time away from your life? And that can be medical care, you know, work, enjoyment. So I'll mention something that's important is when patients have an acute cardiac event, and these patients have, for example surgical procedures throughout their lives there's gonna be a period of adjustment, right? Their mood is probably not gonna be great, they're gonna feel anxious what's gonna look like afterwards? And that's normal. But if the symptoms persist to the point where it's not getting better, they're not able to sort of, go back to where they were or or be able to readjust to this new normal, that's also when we wanna be cautious about.

Dr. Burchill: Right, and you mentioned a term that I think people will be interested in, you said psychological distress. I mean, this could be something we say just in a layperson language, but what do you mean? What is psychological distress? And what factors are contributing to psychological distress in addition to what you were just talking about?

Dr. Suarez Pardo: Yeah, I like to use a term because it's a little bit broad in the sense that it's not only about depression or anxiety it just really covers a lot more than that. So it covers, for example, stress it covers, for example, grieving. So when we have health problems, we lose, we lose health. And that's sometimes we have to really grief, you know part of our health. So when we think about psychological distress, it's this really umbrella term of all the different areas that can affect our emotional wellbeing.

Dr. Burchill: Yeah, and we've talked about, you and I can we move beyond mad, bad and sad? They're sort of the three categories that, that so many of our patients are lumped into, mad, bad and sad. And you've shared with me, you know there's just a much broader range of psychological distress but also emotional expression, for how we experience our health and also our illness.

Dr. Suarez Pardo: Yeah, and I think that's really important that I will add that patients with cardiovascular illness actually have specific symptoms related to their cardiac health. So there's actually anxiety specific to their heart or cardiac anxiety and there's actually questionnaires for that. But what's important about it is that it really, it's different than the general anxiety that a patient would share with their providers. And sometimes it's just this fear or you know, emotional connection with their heart and heart situation. And sometimes it gets overlooked because nobody qualifies that anxiety and that distress with what we know generally about anxiety. And those patients can still having a high degree of distress and emotional difficulties that we are missing. So it is important to get outside of the what we typically see in the general population and really look at this specific group and how they struggle.

Dr. Burchill: Yes, I had two patients last week and just talking about heart related anxiety actually being something, it's real. We can define it, it's separate to general anxiety. I think that they found that very helpful. It sort of validated that it's okay to have anxiety specifically related to their heart history, their heart condition, and also something you mentioned earlier uncertainty about the future, which I see as being a key struggle that many of my patients have. They use the language of it's this cloud that hangs over me, or they might say I have to work myself up in preparation for every visit because this could be the visit where I'm told that I need to have another open heart surgery.

Dr. Suarez Pardo: Yeah, and that brings me to the trauma, right? So when we think about traumatic distress and PTSD in this population, it's not, you know the typically term that we sort of commonly know about you know, being exposed to a natural disaster or maybe those who are in the military, but it's really about this chronic sort of built stress. And there is actually a correlation with chronic stress and then the development of more formal trauma. And patients since childhood have had, you know stressful situations that are traumatic and we sort of you know, they roll with us and they get older treatments and they keep going, but as you said, they come to an appointment and then there is another difficult step or a difficult news they have to get, and then is they're building into that chronic stress and then the trauma. And when we think about trauma, it's complicated because that means the threat or the alarm system is really vulnerable. So when you take that patient again to another procedure that's gonna impact, you know, recovery. So I think identifying that, it's gonna be helpful and not everybody experiences that, but I think it's a very also prevalent, also up at the 20% for these patients.

Dr. Burchill: Right, and does this also, are you talking about a formal diagnosis of post-traumatic stress disorder?

Dr. Suarez Pardo: Correct.

Dr. Burchill: Yeah. And so what sort of treatments are available for patients who have post-traumatic stress disorder?

Dr. Suarez Pardo: So I think the first thing is recognizing it and really sort of understanding why they react. When people have post-traumatic stress disorder, they react to ch to stressors very differently, right? They're very vigilant and they're very aware of what's happening but they don't know why. Being comfortable within their bodies is gonna be difficult, and anything is gonna feel a lot more sensitive. So giving them the chance to understand that it's important. And then psychotherapy is important. So we do usually cognitive behavioral therapy, and just giving them tools to really process what's happening and be able to connect the thoughts, with their emotions and then their bodies and behaviors. 'Cause oftentimes people, or we think about that differently, right? But one thought that gets into our mind, even one memory that goes through our mind can just develop a chain of things, from emotions to behaviors, to things that would avoid someone to go to a doctor or take a medication just because the memory started it all. So being able to connect all of those pieces for the patient is helpful. And then helping them get skills to regain the confidence about themselves and their bodies and know that things will be fine. There's also pharmacotherapy, so antidepressants can often help especially when the anxiety and depressive symptoms are commonly comorbid with trauma. So if that is really getting in the way, then pharmacotherapy can be of benefit.

Dr. Burchill: You know, I see so many patients where I think that this is a major issue, and they have not got a formal diagnosis. What's interesting to me is that these patients can become the frequent flyer group. They can become the patient that's calling the office regularly, that keeps returning because they have pain, palpitations they have, it seems that they have a level of concern or upset related to their heart symptoms that are disproportionate to what we might find when we test with a halter monitor or you know, we observed them in hospital even for a period of time. So I'm interested, just as we sort of get to the end of this conversation, what do we as clinicians need to do to really reflect on how we are approaching these patients? And just to lead in, to provide some further sort of framing for this question, my patients often get labeled as being being crazy and difficult and problematic, particularly for people that are not used to caring for adults with congenital heart disease. So there's a stigma associated, I think with having congenital heart disease. But you've explained so well, part of why they've ended up in the place that they end up because of this journey that they've been on. So what about if we sort of flip the focus from the patient to the clinician, someone who might be listening today, what work do we need to do so that we're actually attentive to these journeys? And able to maybe look beyond the frequent chest pain and palpitations and start thinking, maybe there's a mental health concern here that has been overlooked.

Dr. Suarez Pardo: So I think couple important things. So the first thing is trust. So a lot of these patients have not really built a trust with the system and even with themselves, right? They're not, they don't feel and some of them don't feel normal and there's always been some limitations,

right? And we know that setting limits to patients not allowing them to exercise, and be doing their regular stuff really impacts how they perceive themselves. So there's really no trust in themselves and the care they receive. So I think being really mindful about we are telling them lots of things and we're explaining them but they might not be listening exactly what we're saying because they don't trust the care they get. Because they've also been sick many times and people don't listen to them, because I think, again, we don't open those safe spaces. So I think recognizing that these patients don't trust us or the system with good reason, and then we need to open those spaces. And then the second thing is, because of the ongoing illness adjustments, the burden of the illness, all the things they've been going through, the uncertainty, their coping skills are different. So when we think about learning good coping skills and optimal emotional wellbeing, that is challenging when you have all sorts of medical problems going on, right? And everybody telling you what you need to do and how you need to do it. So the coping skill might not be the same as someone who's healthy. So calling multiple times or even expressing pain, can be one of the coping skills or their way to just say, I need help. So when we think about someone who's chronically complaining of palpitations of pain, I think one of the things that clinicians can think about is that means that someone is struggling. And maybe it's not their cardiovascular system that's giving them trouble, but something else is happening. So I think that's when we have to ask, right? Be able to listen, maybe assist patients, you know if you have some ideas of how they could navigate things a little easier, but if things are really complicated then arrange treatment and be able to guide them to the right resources so they can do that. Pain is interesting because when people are depressed, when there's trauma, the pain experience is gonna amplify. So patients are gonna feel more pain and be more sematically focused when they're having mental health concerns. So that should be another sort of red flag for clinicians to say maybe they need some psychosocial support that we're not delivering.

Dr. Burchill: I think this has been so valuable. Just to summarize those last comments, I work hard to rule out, you know the dangerous and the life threatening. So you know, the patient that comes in with palpitations, I don't want them to be having ventricular tachycardia, I don't want them to be having super ventricular tachycardia I feel they flooded that we're missing. But I think what happens is that we rule those things out and then the clinician perspective is, well you don't have a significant rhythm problem. And that is different to what you were just explaining, that is quite different too. You have significant palpitations, that are important for you, that we need to understand in your daily life and also understand how it fits with within your sort of explanatory model, for your life, your health, who you are, and we can work together on that. I think that that's such valuable advice because that's where I see a lot of the tension rise between the cardiologist and the patient. We're saying there's nothing significant, the patient's saying, this is really significant for me and we're unable to have a dialogue about it simply because we haven't confirmed a diagnosis of SVT or VT, just as an example.

Dr. Suarez Pardo: Yeah, it's the rule in versus the rule out, right?

Dr. Burchill: Yes, yes. So I think that, I'm hoping that people are listening today and this might translate to perhaps that creating the safe space that you just mentioned, taking a step back, thinking about what some of the symptoms that people are presenting with, some of the distress that people are communicating in their clinic visit, what does that mean for them? How is it influencing how they interact with us and how they communicate in their clinic visits? And as

clinicians, what is the broader range of supports that we might be able to call on, including our mental health professional colleagues so that we can better support not just the patient but ourselves, because I can say, put my hand up I'm not a psychiatrist, I'm not a mental health specialist, I know that I need you and people like you.

Dr. Suarez Pardo: Yeah, and I think that's actually a very important point, is collaborating. I think we cannot really care for patients alone, right? So we need to really work in interdisciplinary teams, reach out to each other and really help the patient in that way, which is probably most helpful.

Dr. Burchill: Well that's a great note to end on. Thanks so much for your time today, Laura. I've really enjoyed this conversation and perhaps we'll have to continue it again depending upon the feedback from those listeners out there. Thank you.

Dr. Suarez Pardo: Yeah, thank you for having me again.

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