INside the OUTcomes: A Rehabilitation Research Podcast

Episode 4: A Phone-Based Intervention for Self-Managing Pain at Work

SHARON PARMET, HOST:

Getting out of bed and going to work can be tough even on the best of days. But for people who experience chronic pain work can be especially difficult, and lots of people who experience chronic pain are under or unemployed because of it. Today we're going to talk about a research project now underway through the Center for Rehabilitation Outcomes Research at Shirley Ryan AbilityLab to evaluate a virtually delivered pain self-management intervention designed for people with chronic pain who want to continue to work. We'll hear from the project's lead investigator Dr. Dawn Ehde, clinical psychologist and Professor of Rehabilitation Medicine in the Division of Clinical and Neuro Psychology at the University of Washington, Seattle. We'll also hear from Mary Curran, a licensed independent clinical social worker at the University of Washington Department of Rehabilitation Medicine. Mary delivers the pain self-management intervention, and we'll hear from Rachel, 38, a nurse at an intensive care unit who says her participation in the pain self-management program has provided valuable tools and techniques she uses to manage pain caused by multiple sclerosis.

And with that, I would like to welcome everybody to the podcast. We're going to start with you, Dr. Ehde. Could you tell me a little bit about this research project? The pain self-management intervention? And what were the reasons for creating this project?

DR. EHDE:

Yes, thank you for having me. As you said, chronic pain is very prevalent, very disabling and very persistent condition that many people experience including people who have what we might call physical disabilities. For example, more than half of adults living with MS or traumatic brain injury, and more than two-thirds of adults who have Parkinson's disease or spinal cord injury experience chronic pain. And as you also might imagine, chronic pain has many negative effects that disrupt sleep, it contributes to fatigue, it puts people at increased fall risk, and it really disrupts people's lives, including their ability to work. So not surprisingly, people who experience chronic pain are more likely to leave their jobs and are more likely to be under or unemployed.

So we decided to tackle the problem of chronic pain and people with physical disabilities because we believe that there are potentially helpful treatments that many people are not getting. We know that medications are often the most common treatment people use for chronic pain. And unfortunately, they rarely provide adequate pain relief, or have side effects. And so what we hear over and over from people with multiple sclerosis and other types of physical disabilities or neurologic conditions is that they're eager to learn new ways of managing their pain such as the ones that we teach in our project, which we'll hear about in a few moments to complement the other things they're doing to manage pain.

SHARON:

Thanks for that overview of chronic pain and how it impacts people. Tell us a little bit more about the E-TIPS project. I know that's what it's called. What does that stand for?

DR. EHDE:

It stands for employment, telephone intervention for pain, and it's much easier to call it E-TIPS. And that refers to both the study and the intervention we're studying. We're just finishing a randomized control trial comparing the E-TIPS intervention to usual care, and people with either multiple sclerosis, traumatic brain injury, spinal cord injury or limb loss, who also have chronic pain.

SHARON:

So what is the intervention and what is the usual care?

DR. EHDE:

The intervention consists of eight weekly 45 to 60-minute telephone sessions with a therapist who's trained in teaching people pain self-management skills that are based on cognitive behavioral therapy. Cognitive behavioral therapy is a type of treatment that involves giving people strategies for managing and coping with symptoms, looking at how their behaviors might influence it.

So for example, teaching people how to pace their activities. We know that self-management interventions such as CBT are efficacious or effective in reducing pain and its negative effects. Multiple studies over and over have shown that CBT is effective for pain. Unfortunately, people with disabilities such as multiple sclerosis or TBI, traumatic brain injury, they're not getting these treatments. And we decided to tackle that by delivering the E-TIPS intervention by phone, so by telehealth, to see what benefits it has for people with pain and a disability.

SHARON:

And you said that it was a randomized controlled trial. So there are other people who are getting what you call usual care. Can you just quickly describe what that is?

DR. EHDE:

Yeah, usual care means kind of what it sounds like. They simply keep doing what they're doing. They don't have to stop any of their pain treatments, but just do what they do. And then at the end, you know, at certain time points, we assess how they're doing, at the end of the treatment, those who are assigned to usual care, they get the opportunity to get the E-TIPS intervention.

SHARON:

I know that the study has been going on for a little while now, do you have any early data that you can share?

DR. EHDE:

Yeah, I can say that study participants have done 90% or more of all eight sessions, which is pretty remarkable. If you were to go to a therapist and a rehab clinic, or a private practice, it's pretty unlikely that you do all eight sessions in a row. We're getting lots of comments from people about the benefits, the treatment satisfaction is very high. And we keep hearing remarks such as you know, why have I not gotten this treatment before? Why is no one offered this to me? Or I wish I had learned these strategies sooner.

SHARON:

Yeah, I see that Rachel is nodding her head on our Zoom call and what we'll hear from her and in a second. So I want to bring it up to Mary, who is the person who delivers the intervention over the phone. Mary, what are these techniques that you are teaching people? And if you can tell us a little bit about why they work or, maybe an example of one especially that you like.

MARY CURRAN:

Okay, well, we teach a variety of techniques, based on cognitive behavioral therapy, so some focus on behaviors. So meaning, like, I think Dawn mentioned, you know, goal setting, or pacing of activities. So a lot of times with pain, things drop away, you know, things that bring you joy, meaning one of the strategies we really focus in on is how do you build back in activity in a slow, gradual way. So that ideally, it's not amping up your pain, but you're also, you know, you're having this reconnection. And we also know that physical activity can be beneficial for pain management if it's done in a, you know, slow, gradual way. So that would be one of the, you know, kind of key pieces.

The other thing that we really work on is working with thoughts or cognitions. And kind of, basically, the meaning people make up their pain experience, because we know that the brain is very involved in pain perception and modulation and kind of, and without the brain in that process. You know, sometimes they'll say, you know, no brain, no pain, and it doesn't mean that the pain isn't real. But we know that the meaning that we make of it can either amplify it, or in the opposite way, kind of turned the volume down on it, sort of the thoughts that we have about it, that influence our experience, you know, the emotions, what we do, how we feel physically. So we work a lot of helping people learn to identify thoughts, you know, that are happening in the background, kind of automatically, what we call automatic thoughts that you may not be aware of, but maybe you start to notice a twinge and, you know, tension in your shoulder, or, you know, an amping up of anxiety, and you might not be as aware of what the

thought is, or helping people to build, you know, understanding of, of that, like an and then to kind of evaluate a thought as either being helpful or unhelpful.

And then really looking at those thoughts that may not be serving us well that are unhelpful, that interfere with our ability to cope when pain arises, I'd say those are kind of the two of the other, those are two pieces.

And then I'd say the third one is really relaxation skills, some skills that you can use in the moment, but also to cultivate what we call the relaxation response over time, and, you know, it takes some time with most of these skills to get the benefit, you know, because the tendency is with pain is, you know, we respond by tensing, that's kind of our habitual response. So we're trying to help people, you know, build that relaxation response, through practice. And that's, I would say, the other little main piece is sort of what happens in between the sessions we really focus in on this are working together. It's a collaboration and, you know, really to get the benefit. It's what happens in between, you know, the time we're not meeting.

SHARON:

So really trying to build on what's working well for folks and then help them problem solve when things get tricky or challenging, maybe for it to be brought to awareness that the brain plays a role in how the pain is perceived. And there are techniques that you can use to kind of deal with the pain or cope with it. And the relaxation techniques might be new to some people that you work with through the program.

MARY:

Yeah, I think so. You know, and I think, you know, people's experience has been often sometimes they've been dismissed for their pain or not believed, right. And so we're really trying to, you know, highlight that the experience is real. We're trying to say, Okay, well, what happens next, and making some choice around some things that can help you in the moment and beyond, you know, to reduce the suffering that pain causes. By looking at our thoughts, by having this sense of self-efficacy or control, there's some things I can do that are in my control. You know, and that's empowering.

SHARON:

I want to bring Rachel in. Rachel and I had a conversation a couple of weeks back. And Mary, what you were saying about how the thoughts and the pain are interrelated, and how you teach techniques that can help recognize unhelpful thoughts to help a as a technique for managing pain. Rachel, you were really talking a lot about that in our phone call the other week. Can you talk a little bit about that?

RACHEL:

Yeah, I think I always knew that I had these negative thoughts, but I didn't particularly identify them. And I think part of the E-TIPS is, like part of the therapy that I went through was identifying the thought and then labeling it as helpful or unhelpful or neutral. And then if it is unhelpful, further categorizing it as like catastrophizing, or like a should statement. And I just had never thought about these negative thought loops that I got myself into in that way. But it really helped to identify them so that I could look at it as an observer and not in the muck, like stuck in it in the moment.

SHARON:

Right. And this is in relation to like the thoughts that would come up with your pain, because you're telling me that you're an ICU nurse, which is a high-stress job, you're on your feet, all the time, your attention is being demanded all over the place, and you're just walking around all day, you're saying that your pain is a lot of it is like tingling and pain in your feet and hands, right?

RACHEL:

Yeah. So before I go, I work weekends. And before I start any stretch, I have numbness and tingling in my hands, and sometimes my forearms. And I didn't recognize that as a cycle. At first, I just noticed that the pain, and the numbness and tingling would come and go. And then as I was talking to Elana, my pain therapist, she was able to help me identify that it was something that happened before work every week, and so is the cycle that I would get myself into

where I would have stress. And I've always had stress before work, but then I just started to have physical manifestations of that stress with MS.

And then during, then during work, I would have like neuropathy, pain in my feet from being on my feet all day, and my feet would just feel like they were on fire. And I got myself into these very negative automatic thoughts. And the most prevalent one I would say was, this is just going to get worse, like this means that it's getting worse, like my brain is getting worse and having more lesions. And it was all circled around the fact that these symptoms meant that my disease was progressing.

SHARON:

So these negative thoughts are associated with pain, stress. And what worked what was a technique that you learned through the E-TIPS program? I know that your therapist isn't Mary, it's another one, Elena. What was a technique that just like a light bulb went on in your head where you were like, this really helps. I'm going to use it all the time.

RACHEL:

Identifying the thoughts and then she had me come up with alternative thoughts, which was I think my favorite part of the whole study was identifying alternative thoughts. So it doesn't mean that I don't have pain, the numbness and tingling still come before every stretch and during my work stretch. I still have neuropathy pain. But when I start to think this is getting worse, I immediately think no, it's not. That's just the automatic thought. And then I switched to an alternative thought that I had come up with during therapy, which, for me, as morbid as it sounds, is, even if I go to hell, I'll find a way to enjoy it, which is like a Zen Buddhist quote, but for me, it's even if my feet and I are in hell, I will find a way to enjoy it because it doesn't mean that the pain is not going to go away. Again. It's just a cyclical thing that for me is manifested because of stress.

SHARON:

So it sounds like the E-TIPS program really helped you hone in on these negative thoughts that were not helping the situation at all. And you've come up with a way to identify the thought and to kind of replace it with a less negative thought to help get you through. What were some of the other techniques that E-TIPS gave you that you've been putting into practice?

RACHEL:

I would say the biggest ones are diaphragmatic, for me, diaphragmatic breathing, which seems so simple, but it's so huge to just take a moment and take some deep breaths and recenter yourself and come back into the moment to be present to give yourself a chance to think about the alternative thoughts and a better way to frame things in your mind.

And then the other big one for me was visualization. Where anytime I feel like my feet are starting to get hot, I will just close my eyes for a minute. Because as you can imagine, in an ICU environment, I can't just take off my socks and shoes, I can't walk around barefoot in a hospital, that'd be disgusting. So I visualize just sitting next to a creek and I can hear the birds and I can feel the cool water on my feet. And I can feel the breeze on my face. And the visualization helps me kind of it helps calm my brain down enough so that I can realize that it the neuropathy pain is still gonna be there, but it makes it more manageable.

SHARON:

And you can do this in a hospital setting.

RACHEL:

Yeah, exactly. It's something I can do at work is just take, I mean, it's a very quick process. For me, I think of my alternative thoughts, I close my eyes for just like 15 seconds, and reframe things in my head. And then I can keep going because I don't have a half an hour to do some of the other techniques. So here's something that I can do quickly in the moment when I'm having pain, which for me a lot of the time as well as when I'm at work.

SHARON:

I'm just curious, have you altered your work schedule? Since your symptoms have come on?

RACHEL:

No, I have one of my other automatic thoughts was I need to find a different job, this is not going to be sustainable, long term. And then I've gotten myself into that thought pattern of I have to find a new job, I have to find a new job, this is not going to work. And then I remind myself one of my other alternative thoughts was, but you can still do everything that you've always been able to do. And I'm good at the work that I do. And it is stressful. But that doesn't mean that it's making my disease process worse. It's just that I have physical manifestations of the stress.

SHARON:

Were you are really considering like, Is this too harmful for me to the point where I should maybe consider something less stressful?

RACHEL:

Yeah, I mean, I was 37 when I was diagnosed. So I haven't been I haven't had MS for a very long time that I know of right? But I immediately thought, do I need a different job? Will I not be able to use my hands? Will the pain gets so bad that I won't be able to be on my feet for 12 hours? And as a nurse, I have the luxury of like slipping into, you know, telehealth or something else where I could still be a nurse, but work kind of behind the scenes from a desk. But for me, that would not be a good option. I'm a very active person. And so the thought of that also brought me grief. I mean, it was like grief over loss of a perceived loss of a job that I love. So when you first started asking me about how this affected my employment, I honestly forgot that E-TIPS was an employment-based study because E-TIPS has helped me in so many different aspects of my life.

SHARON:

Wow, that's so good to hear. Tell us a little bit about your life outside of work and how the E-TIPS techniques have played in on in those areas.

RACHEL:

I have a very energetic five-year-old nutball have a daughter. And oftentimes, as you can imagine, life is hectic with a five-year-old. So the diaphragmatic breathing is one that I can do anytime, anywhere, especially when we're just having a rough day. So I will take you know, five to 10 deep breaths and that helps reset me. But it also helped reframe all of the grief and the loss that I'd had around the diagnosis of MS. Because I honestly had a series of identity crises is one of them about being a mom and not kind of living up to the mom than I'd hoped to be. And thinking that, you know, this diagnosis just means that I'm going to become disabled in the future and I'm not going to be able to pick her up and I'm not going to be able to run with her.

And there's just so much uncertainty with this diagnosis, which is really hard for somebody who struggles in general with being a control freak and fear of the unknown is really a crushing feeling.

And it helped me like the alternative thoughts that I learned any tips really helped me reframe everything in my life. Because now anytime I feel grief or a loss, or perceived future pain, physical pain, emotional pain, any of it, I can come back to my alternative thought of, even if I go to hell, I'll find a way to enjoy it. And that might not be everybody's alternative thought but for some reason it snaps me out of it.

SHARON:

I think that is a great place to wrap the episode.

I want to thank my guests Rachel, Dr. Dawn Ehde and Mary for joining me on this episode speaking about E-TIPS. Thanks so much for your participation.

This has been INside the OUTcomes: A Rehabilitation Research Podcast. This podcast has been supported by the National Institute on Disability Independent Living and Rehabilitation Research.

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