

INside the OUTcomes: A Rehabilitation Research Podcast

Episode 13: Spinal Cord Injury and Mental Health

SHARON PARMET, HOST:

Welcome to INside the OUTcomes: A Rehabilitation Research Podcast from the Center for Rehabilitation Outcomes Research at Shirley Ryan AbilityLab. I'm your host, Sharon Parmet. On this episode, we'll be talking about a big topic, spinal cord injury and mental health. We'll learn about some common mental health challenges that people face after spinal cord injury, and about a Center for Rehabilitation Outcomes Research project funded by the Craig H. Neilsen Foundation that seeks to better understand and support the mental health of people with spinal cord injury.

I'll be speaking with Kaylee Dragna, a clinical psychologist at Shirley Ryan AbilityLab and with Jenny Burns, project manager for the Neilsen spinal cord injury and mental health research project. Welcome to the podcast, Kaylee and Jenny.

KAYLEE:

Thank you.

JENNY:

Hey, thanks for having us.

SHARON:

Kaylee, I'd like to start with you. So you work directly with people who have spinal cord injuries at Shirley Ryan AbilityLab? What are some of the common mental health challenges you see your patients face in your practice?

KAYLEE:

Yeah, so definitely. I think the spinal cord injury in particular, if we don't have friends, or family or models, I think there's just a big adjustment that people go through understanding what a bowel and bladder program is or needing help with the bathroom. So there's a lot of anxieties and fears that come up that I see a lot of, and a lot of adjusting to how they see themselves. So, you know, I'm now a wheelchair user. And I've never been a wheelchair user before. What does that mean for what does that mean for the future? And so I think a lot of what I do while on the inpatient side at Shirley Ryan AbilityLab, when they first get here, is talking about, Wow, this just happened. And yeah, this is scary. Let's take it one day at a time, let's not find ourselves getting too overwhelmed or looking too far into the future. Because our brain likes to play plenty of tricks on us and doesn't tend to think of best outcomes. And to kind of think of you know, what could go wrong? So a lot of it is just taking things day by day, a lot of education about the process, and what's kind of normal to go through those normal ups and downs that come with all injury and illness recovery. And that's it. That's a lot what I see in this like immediate time right when people get to Shirley Ryan.

SHARON:

So it sounds like a lot of the work you do centers around education as well as just bringing people through their feelings and how they see themselves after spinal cord injury, because like you said, it's not something that everybody knows much about. So do you find that the educational component helps take people's mind off it for a moment? And they're just focusing on learning? Or how does that work?

KAYLEE:

Yeah, I think what's important with the education is that it normalizes some of the things they might be going through. A lot of the time people, you know, maybe they feel uncomfortable, because they're having a nurse help them use the restroom for the first time, when I normalize it, and I say this is a part of it. And yeah, those feelings of like a lack of privacy or things that I'm embarrassed to ask for help with. A lot of patients experience this. So I think normalizing it and reminding them that this is a something that to be expected and something that we are equipped to handle, because we've seen it before, I think. And a lot of education, too.

I actually work with the staff to kind of remind them, this is new for the patient. Yes, we see spinal cord injury every day. It doesn't mean anything to us to see a patient in a Hoyer lift or needing help to go to the bathroom. But it's new for the patient. And so a lot of just that education about like this is what's new, and this is what what's to be expected, I think kind of helps lay that foundation of, oh, this, this is normal, right? Because it feels like maybe a really big deal for them. Their world has completely changed. So I think just saying yes. And other people have been through this. You're not, you know, it's not pathological to be feeling this way. Right.

SHARON:

Do you see a lot of people fall into depression early on or kind of withdraw?

KAYLEE:

Yeah, I think that's something I see especially more as like, people move into like the day rehab setting. That withdrawal is really big. I see a lot of kind of shock and denial, which if we're thinking about in the context of grief, right? We've just lost some maybe physical function or privacy or independence. That shock and denial, I see a lot of impatience and I see more of that like maybe anger with the situation or with the world or with their higher power.

They're in a lot of that depression. And I think too, particularly with spinal cord injury, I see people who get in a really bad habit of, it becomes a chore to leave the house. I need someone to fold up my wheelchair, I don't have a, you know, power wheelchair accessible van. So they only leave the house to go to doctor's appointments and therapies, and they're not doing the things that they enjoy to do like going to dinner or going to a show or the movies. And I think a lot of that to that isolation, not just because it's a chore to leave, but people feel judged by others, you know, I, I can't tell you how much I hear people who use a power wheelchair say, this seems like a walking red flag or a big sign saying, Look at me, you know, I have a disability. And so that fear of being judged, I think keeps people at home and kind of feeds into that social withdrawal, feeling down feeling hopeless, because how can you imagine a life with this new function, if you're not experiencing life, you know, if you're only going to the doctor.

So my big thing that I preach, I'm sure if my patients are listening to this, they will laugh because it's a go to, but I tell them, we can manage those 10 minutes of feeling uncomfortable getting ourselves to the outing, we then get to have a good time, right? We can manage that, but they're gonna look at me, but they're gonna ask questions, if we can manage those 10 minutes of getting through that we get to do the fun thing. So I think it's a lot of that, again, normalizing that experience of like, this is a this is anxiety provoking, this is different, and then helping them through it, for sure. And to see that there's a reward on the other side.

SHARON:

So how do you work with patients when they're in inpatient? Is it something where you meet with a patient every day? Or a couple times a week? Or as needed? How does that work?

KAYLEE:

Yeah, so inpatient, every person, every patient on every floor gets seen by psychology within their first couple days. And we kind of work together to see what's the best follow up schedule. I would say the vast majority is one to two times a week. Inpatient is a pretty, you know, busy world, it could be a boring world, it's kind of nice to have someone to talk to and check in with. And then as people move into my other setting at a day rehab, where it's more

of an enhanced outpatient, I see them for a one hour session, usually one time a week, sometimes bi weekly, like every other week, if they feel like they're doing pretty well.

SHARON:

Do you see the mental health issues shifting and changing as people exit the kind of immediate aftermath and the education and the acclamation, and as they go into a go back to their homes or with their families, and they're on a long journey of rehabilitation? In day rehab, do things change?

KAYLEE:

Yes, absolutely. That's such a great question. Because it's, it's a very different like, situation when people are going back home. So I'd say one of the other really big things besides that maybe withdraw from doing the things we did before I see roles are changing.

So people went from, you know, it's my mom, or it's my spouse to now my mom slash caregiver, my spouse slash caregiver. So there's a lot of roles that get renegotiated and they're having to navigate for the first time. When people have their partner acting as their caregiver, there's a new power differential, you now need help from your partner in a way you didn't need before. Are you guys putting off other things like, you know, partner intimacy and going on dates, because you're doing the things that need to get done when we have a spinal cord injury, like doing a bowel and bladder program.

So a lot of that I think, comes up too, and causes just some, some bumps in the road. It's important, I think, to talk about, and I always refer people to, there's really great, you know, support groups for both the caregivers and the patients to, you know, meet with people who are also going through it, and who are also understanding and navigating it, because it is a normal part of this adjustment. It's an adjustment for your entire family and the people who love you. And I think that is a big thing that comes up in the day rehab when people are getting back to their normal, normal, quote, unquote, lives, is these roles have changed. We now need new things. And maybe I'm the one who normally cooks dinner, but now my kitchen is not accessible. And now that's another thing on my partner's plate. So that is something I think that we see and talk about a lot are those changing roles.

SHARON:

And you mentioned family and friends being so important to the process. Do you meet together with the family and the patient?

KAYLEE:

Yeah, so when we're inpatient, we kind of have the freedom to we can even meet with family without the patient present. You know, if they're having a hard time at a rehab, we do family sessions, but the patient has to be present there because you can't be in two places at once in day rehab, so you can't be in PT and being seen by psychology. But I do a lot of family sessions. A lot of I think that education piece goes a long way with the family to who they are going through it too. But maybe the family doesn't have a good understanding of what a spinal cord injury is or what it takes. Another thing that I teach a lot with the education with the family members, is with a spinal cord injury, the effort someone puts into their physical rehabilitation is not always equivalent to the physical gains that they make, right? Someone could be giving 110% at every PT and OT session, and they see minimal or slow progress. And I think that can be disheartening. Because, you know, if I'm the partner, or if I'm the family member, I love that person. And I want to see them, you know, succeed. So that's something I do some education about setting those expectations and just kind of giving like self-compassion and grace, that that's not the way that this works. And that's okay, we can be sad that that's not the way it works. And we can grieve that in the long term.

SHARON:

What do you think some of the mental health issues are that people grapple with years later, decades later? Or that kind of timeframe?

KAYLEE:

Yeah, I think if we have good habits, towards the beginning of recovery, like going to activities, seeing our friends, maybe getting involved with like adaptive sports, or getting back to work or doing those things, I think people have really great long-term outcomes. I think it's when we get into those bad habits. Or maybe if we're not ready, when we first leave the Shirley Ryan umbrella to like, join an adaptive sports team or meet a peer mentor. I think people can find themselves feeling isolated, even those years down the road. So I feel like that's the biggest thing is kind of encouraging people gently to making sure that they're creating good habits now. And they're learning that this is possible as earliest as they can in their recovery.

SHARON:

I want to bring Jenny and now. Jenny's project manager for a research project funded by the Nielsen Foundation that looks at mental health issues among people with spinal cord injury. Jenny, can you tell us a little bit about the grant?

JENNY:

Yeah, of course. Thank you. So we're in the final stretch of a three year project. It began in April of 2021. And as you said, it's funded by the Craig H. Nielsen Foundation. The principal investigator is Dr. Allen Heinemann. And the project was designed to address the gap in knowledge related to mental health outcomes and treatments for people living with spinal cord injury. And although evidence shows that people with spinal cord injury have a higher risk of having mental health issues, or mental health comorbidity, there are not very many spinal cord injury specific systematic reviews available to inform evidence-based treatment plans.

So people with spinal cord injury living in the community already experience so many barriers to receiving high quality health care, like accessibility insurance, some of the things that you were just talking about, and mental health care can sometimes take the backseat. And clinicians need evidence-based information to make treatment decisions. And then people with spinal cord injury need digestible information that they and their care partners can use to figure out where to start.

So the project just to quickly summarize, we had four aims. The first one was to conduct focus groups to identify which mental health topics were most important to people living with spinal cord injury and their clinicians. Then based on those results, and the evidence that already exists in the literature of previous studies, we developed systematic reviews. So we picked those topics and did kind of a whole search of the research literature to try to summarize what treatments and interventions were appropriate for these main topics. And then the third aim involves disseminating the results of these systematic reviews specifically to professionals, so mental health professionals or general clinicians who serve people with spinal cord injury. And then the last aim is to create the consumer-friendly information. We're planning to make some infographics and things that are easily more easily digestible about how to access relevant resources. And as I said, how to start.

SHARON:

So you talked about the Advisory Council and convening this group to talk about or to identify areas of focus for the research. Can you talk a little bit about the Advisory Council and what questions you asked them and how they came up with specific topics and what those topics are?

JENNY:

Yeah, so we use the Advisory Council, which is a group of experts in different areas related to this project. So we had mental health experts, people living with spinal cord injury, rehabilitation, clinicians, doctors, nurses, all that kind of stuff, and they helped us develop the focus group guide.

So that is what we used when we did these focus groups with people actually living with spinal cord injury and clinicians to make sure we were getting out the right questions. And the Advisory Council helped us with that. And then they also kind of helped us, I guess, dissect the results of the conversations that we had in the focus groups. So it's really helpful to have an advisory board there to give input as experts.

SHARON:

What were you discussing with them? Or what were you hoping to get out of the focus groups?

JENNY:

Yeah, so we did five focus groups, three of them were groups of people living with spinal cord injury. So the consumers, we called them, of rehabilitation services. And most of them also had some comorbid, mental health disorder. And then one of the focus groups was with mental health professionals, specifically with experience working with people with spinal cord injury. And then one, the last group was with rehabilitation clinicians, so like physical therapists, OTs, doctors, with experience working with spinal cord injury. And the main question we wanted to ask is, what are the most important topics that you think impacts the mental health of people living with spinal cord injury out in the community? So we identified a few themes from that. And that kind of spearheaded our focus group findings, and then our systematic reviews.

SHARON:

So what were the areas of focus that you came up with?

JENNY:

Yeah, so first, we call it mental health challenges, because actually, most people did not talk about specific mental health disorders that had been, you know, diagnosed by a mental health professional. People spoke a lot more about symptoms or experiences that they felt were impacting their negative, or their mental health negatively. And some of these challenges, again, as we touched on earlier, anger and frustration was a really big one, loneliness and social isolation, and just overall depressed mood. So that was kind of our the answer to our main question.

And then our second theme that came up a lot was, again, like we talked about earlier, this the timeline of mental health supports, and versus the treatment of their injury, and you know, the setting that they're getting their treatment. So basically, people have the most support in inpatient rehabilitation, right after they're injured. And a lot of people are dealing with some of the things that Dr. Dragna mentioned earlier, like shock, denial, anger, just trying to focus on therapy, and the physical and medical issues that they're dealing with getting used to their injury. And then suddenly, there's a drop off, they're discharged, they go home, and life kind of continues to move on. And people talked about feeling like when they were ready to receive those resources, and that psych information, they didn't have it anymore. So kind of that timeline of when we offer support to people.

And then the third theme was this topic, we called it disability identity. But it's really the grief and the process of forming a new identity and kind of mourning your previous role in society and in your family structure. And, yeah, the dissonance of resolving those two issues and creating a new identity that merges your disability with your personality and your original role.

So the last theme, we call that adaptive resources. It's what people voiced as the best coping strategies that supported their mental health. And social support was really the main theme that came up related to that. This included both social support from family and friends. And then especially the SCI, spinal cord injury, peer support, so interacting with other people with spinal cord injury and kind of having that community and eliminating that social isolation that kind of gets people into the cycle of negative mental health.

SHARON:

Dr. Dragna this all sounds like the exact same stuff that we just talked about at the beginning. And it seems that incorporating a new idea of yourself into your identity seems to be something that take a really long time. Do you have any experience with helping people to integrate this new aspect of themselves?

KAYLEE:

Yeah, definitely. I think that's a really important piece is kind of exactly the way Jenny was explaining more that maybe what we've imagined for ourselves or what we had hoped for ourselves and coming up with how do I still honor that person? I you know, how do I still do the things I love to do maybe in a new way.

So one of the things I think that we really do a lot of work on as psychologists with all types of injuries, but especially spinal cord injury that really impacts mobility is looking at what do I value in those things? So I've had people say, I'm an ultra-marathoner, and then here I am now using a wheelchair. Well, what did you value in being an ultra-marathoner? Was it pushing your body to extremes was it being outside was it being part of a team, because we can do those things and we can honor those things that you like, in new ways. And so I think that's a big part of it is incorporating our new level of functioning or new mobility, but still doing the things we love to do. And reminding ourselves like our lives did not end that day, it just looks different. And we can continue to move on in a new way. And I think that's more of the like Jenny was saying, kind of incorporating it, that identity piece of I am still who I am. And I can still do the things I want to do, it might just look different.

SHARON:

So Jenny, you found with the focus groups, you identify these areas of interests that people wanted more information about wanted to focus on, after that, with different topics, and have turned into systematic reviews, where you're searching the existing literature for information on these topics, to synthesize what's out there and report back out. Other than the systematic reviews, what else? What else is a project about?

JENNY:

Yeah, so the systematic reviews are really helpful for just summarizing the literature. And a big part of that was also seeing what already existed, like there was just a paper that came out recently about interventions for social isolation and spinal cord injury. So we focused you know, a little less on that because other researchers were already doing it.

But then I think the main part of this project that we are hoping to work on in the final stretch, is getting the information to clinicians and to people living with spinal cord injury. So continue publishing systematic reviews, with recommendations for clinicians, presenting at conferences, that sort of thing. And then for consumers, or people living with spinal cord injury and their care partners, our goal is to create infographics or kind of quick guides, like fact sheets about what resources are available, maybe like what kinds of signs and symptoms should you be taking note of and how to talk to a health care provider about your mental health following spinal cord injury. So that's how we're really hoping to get the information out into the community.

SHARON:

I look forward to seeing that information and as the healthcare communications associate at the Center for Rehabilitation Outcomes Research, I'll probably be working on some of those pieces myself.

JENNY:

Yes.

SHARON:

Thank you. Thank you both so much for being on the podcast. This has been really interesting and informative.

JENNY:

Thanks again.

KAYLEE:

Thank you so much. Nice talking to you both.

SHARON:

This has been INside the OUTcomes: A Rehabilitation Research Podcast. This podcast is supported by the National Institute on Disability, Independent Living and Rehabilitation Research. This is your host Sharon Parmet signing off.