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Episode 26: Loneliness and Spinal Cord Injury
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On this episode of [INside the OUTcomes](https://www.sralab.org/research/labs/cror/projects/inside-outcomes-rehabilitation-research-podcast), we will be talking about loneliness and spinal cord injury. My guests are [Dr. Sherri LaVela](https://www.cmc3.research.va.gov/docs/Sherri_LaVela.asp), a research health scientist, and Marissa Wirth, lead social science program coordinator, both in the [Center of Innovation for Complex Chronic Healthcare](https://www.cmc3.research.va.gov/index.asp) in the Department of Veterans Affairs. Dr. LaVela is also a research professor of physical medicine and rehabilitation at Northwestern University. Dr. LaVela and Marissa have extensively studied how loneliness affects people with spinal cord injury and have uncovered factors that contribute to and alleviate loneliness in this population. They've also developed some great resources on the topic, which we'll talk about later. Welcome to the podcast, Dr. LaVela and Marissa.

DR. LAVELA:

We’re happy to be here. Thanks for having us, Sharon.

MARISSA:

Yes, thank you for having us.

SHARON:

Before we get into loneliness and spinal cord injury, let's first just define what loneliness is. Marissa, can you walk us through that?

MARISSA:

Yeah, great question. So throughout literature, concepts related to isolation have many names and multiple definitions, but really they divide the isolation construct into two independent constructs of subjective and objective components. So subjective social isolation, which is perceived social isolation, but we commonly refer to that as loneliness. Now that is going to be the feeling of being left out, isolated, avoided or detached from others. Whereas the objective measure of social isolation is the inadequate quantity of social interactions or relationships. And that's something that's quantifiable. So that's often measured by things such as social network size and frequent contact with others or lack of engagement in activities. So loneliness and objective social isolation are related, but they're two separate constructs.

So to give an example of what I mean. So somebody can be living in a home with their family, see a big group of friends often, but when they are around these individuals, they may often feel alone or detached. So they may feel loneliness, but quantifiably they're not socially isolated due to having that larger social network size. And then conversely, someone may be socially isolated since they have a small social network, but those connections are socially meaningful to them, so they are not experiencing loneliness.

**SHARON:**

So are individuals with spinal cord injury more likely to experience loneliness than someone who does not have a spinal cord injury? And why might that be?

DR. LAVELA:

So first, I'd like to point out that in recent years, we have all seen more attention to this problem of loneliness and its increased prevalence. And this is really because people have taken notice of the significant threats that loneliness can have on someone's health and well-being. And also that loneliness can and does affect a wide variety of people.

Also, a recognition of loneliness has been brought to the forefront as a result of the Covid-19 pandemic. In fact, this year, the World Health Organization recognized loneliness as a global health, public health priority. And last year, the U.S. Surgeon General identified loneliness as an epidemic and issued an advisory on loneliness, along with a call for action.

So to answer your question, in the population of individuals without spinal cord injuries, rates of loneliness have typically been reported to be about 30%. And since the Covid-19 pandemic, those numbers are closer to 40%.

But in [our work](https://pubmed.ncbi.nlm.nih.gov/38281576/) and work of others in the spinal cord injury population, about two thirds or 66% have reported having loneliness. And interestingly, this rate has consistently been higher in this population than among individuals without SCI.

As far as why individuals with SCI might be more at risk for loneliness as well as other social inequities, there are many reasons. First, after spinal cord injury, people often struggle with changes in their social roles or their life roles. And this can severely impact their social relationships. Many people with spinal cord injuries that we've spoken to have described feeling like a burden, feeling no longer able to contribute. And many have perceptions of no longer belonging to the groups that they were part of pre-injury. And all of these factors can cause them to disengage and to avoid social interactions entirely. And this is a big problem because research has already shown that after spinal cord injury, individuals tend to have fewer people in their social network. They often have strained quality of relationships. And all of these factors can result in fewer social interactions.

In addition, things like impaired mobility, transportation difficulties and access issues can contribute to barriers to social participation. So sometimes people can't get to places. And even when places are accessible, sometimes people may not feel comfortable navigating the crowds in a wheelchair.

Another factor is that individuals with spinal cord injury face many secondary complications due to their injury. These are things such as chronic pain, bowel and bladder dysfunction and spasticity. And each of these factors can make going out and socializing more difficult and ultimately less desirable for people with SCI. Some individuals told us that they avoid going out entirely because they're afraid of having a bladder accident in public and others run into problems with things like not being able to find a place to change their catheter, say, for instance, if they attend outdoor high school sporting events.

SHARON:

So how does loneliness affect people with spinal cord injury?

MARISSA:

Yeah. So in general, loneliness is associated with an increased risk of all-cause mortality about 22%. So to give some context of what that means, so that's as much as smoking up to 15 cigarettes a day.

Loneliness has also been associated with a variety of health concerns. So things like a weaker immune response when exposed to infectious diseases. Also having physical responses such as a heightened inflammatory reaction to stress. Also in late 2022, the American Heart Association published a study that showed loneliness can increase the risk of heart attack and stroke by 30%.

So also, loneliness is associated with negative effects to mental health. So things like depression or anxiety or decline in cognitive function. And individuals with SCI can experience all of these adverse health effects associated with loneliness. And then they can also experience even greater chronically-occurring secondary health conditions.

So like Dr. LaVela previously noted, things like bladder and bowel dysfunction or UTIs or chronic pain. And I also want to kind of highlight some of our current research we've been doing that loneliness may impact individuals’ participation in lifestyle behaviors. So we found that individuals with SCI with moderate to high levels of loneliness had poor eating habits, poor sleep and less leisure activities.

SHARON:

I know that you've published many, many papers on loneliness and social isolation and isolation in general among people with spinal cord injury. Can you talk a little bit about your research on these topics and share some key findings?

DR. LAVELA:

Sure. So I'll tell you about our two most recent research studies on loneliness. One was funded by the Craig H. Neilsen Foundation. And the early goals of that [study](https://chn.dimensions.ai/details/grant/grant.12919962?search_mode=content&search_text=lavela&search_type=kws&search_field=full_search) were really to understand what drives loneliness. To help us understand also what the potential contributing barriers and facilitators might be. And then also we wanted to hear directly from individuals with a SCI about what their preferences might be for loneliness treatment. In other words, how might we help them manage loneliness in ways that matter the most to them?

The next step of the study was to use this information to develop an intervention that is intended to alleviate loneliness. And this intervention was co-designed by key stakeholders. And this included feedback from individuals with a SCI as well as spinal cord injury health care providers. The intervention is called [Caring Connections](https://pubmed.ncbi.nlm.nih.gov/36400737/), and we've recently implemented it using a randomized control trial design. And the results of this are currently being analyzed.

So to tell you a little bit about this intervention, the Caring Connections intervention. It's peer-based, it's facilitated, and it is a recurrent letter writing program that's designed to provide what we're calling ‘moments of positivity’ to reduce loneliness and people with an SCI. It was developed using the early preliminary data that I just discussed that we collected from stakeholders. And this was so that we could tailor the interventions specifically to meet the needs of people with an SCI.

The Caring Connections intervention is based on the principles of the broaden and build theory of positive emotion. This is an interesting theory that suggests that micro moments of positivity, which in our case are in the form of caring messages or letters, can foster feelings of belongingness and undo the effects of negative emotions, and most importantly, can create positive emotions that improve social health. And these positive emotions can build an individual's psychological resistance which encourages positive behaviors such as taking the initiative to adapt to or find ways to cope with the challenges that may come with having a disability such as spinal cord injury, an important principle.

The theory is that these moments of positivity can occur between anyone. So this can be from a close friend or a family member to a stranger. And also these recurrent experiences of positive emotions can accumulate over time to put people on a positive path of growth and social health and hopefully to decrease loneliness.

In our Caring Connections intervention, the micro moments of positivity are provided over a six-month period. This was again decided by our preliminary work where we asked people how long they would want to receive the intervention. And what happens is that a volunteer peer who also has a spinal cord injury sends monthly non-demanding letters. And to clarify here, non-demanding means that the contact is initiated by the letter writer and that no actions or demands are placed on the recipient. The letter recipients are individuals with spinal cord injuries or disorders who previously indicated to us that they are experiencing moderate to high loneliness and that they're willing to try the letter writing program to receive letters from a peer with SCI. So the research team facilitated communication. We also tried to match the peer letter writer to the letter recipient on key characteristics that they identified as being important, such as level and duration of injury and age. And so far we've received very positive feedback about people's experiences and we received high satisfaction ratings with the intervention.

So the other research project was funded by the Paralyzed Veterans of America. And the key goal here was to develop an educational curriculum, and this one is geared toward health care providers. The goal of which was to help them identify loneliness and people with an SCI and also to offer ways to help manage care around loneliness.

Both studies use mixed methods, research, and this means qualitative and quantitative approaches. So this included a large scale survey with individuals with SCI. And we also conducted in-depth one-on-one interviews with individuals with SCI, as well as SCI health care providers. So the interviews with health care providers helped us to understand cues to loneliness that health care providers can use to help them be aware of and identify loneliness in this population. In the interviews with individuals with SCI revealed their ideas on how best to reduce loneliness if it does occur, or how to try to avoid it, if possible in the first place. And more so, the survey of veterans with SCI. Maybe you can speak to that, Marissa.

MARISSA:

So we recently conducted a [national survey](https://pubmed.ncbi.nlm.nih.gov/38315055/) with veterans with SCI to examine associations with perceived social isolation or again, more commonly referred to as loneliness. So we found that over half of respondents with SCI had perceived social isolation mean scores higher than the general population. We also found that having a smaller social network size and having depression, anxiety and post-traumatic stress in the past six months and having four or more chronically occurring SCI-related secondary health conditions were associated with perceived social isolation. We also asked respondents to identify the most common contributors to their feelings of perceived social isolation, and those type responses were having an SCI in and of itself also having mobility challenges and then concerned about being a burden on others.

DR. LAVELA:

And if I may, I'll add that in the [interviews that we conducted with individuals with SCI](https://pubmed.ncbi.nlm.nih.gov/38271018/), this was the qualitative work. They emphasized the need to change one's way of thinking after having a spinal cord injury. So they described this as learning acceptance and embracing what they termed as the new normal. They highlighted the importance of taking actions to expand participation in life. So here they emphasized pursuing interests. And they specified that this should be done even if adaptations are needed.

So, for example, we had one individual who was part of a motorcycle club prior to his injury, and he still wanted to be part of that club. So he had a motor trike that had four wheels adapted for him so that he could still participate in this group activity.

Individuals also stressed the need to be involved with others, often stating that even if you have to force yourself to do it, please make sure that you interact with others. They said that this could be in-person online, in writing, by telephone or text one way or the other. Be sure to connect with people.

And then they emphasized also to connect with the SCI community as a way of reducing loneliness. They also highlighted that when. Loneliness does become serious, or it occurs alongside other mental health conditions, things like severe depression, that individuals should seek help from health care providers.

SHARON:

So are there any resources out there that people can access that might provide some information about how to reduce loneliness among people with spinal cord injury?

DR. LAVELA:

Yeah, there are, in fact. Thanks for asking.

The educational curriculum that we developed provides greater details on all the topics that we discuss today and more. It's a resource with suggestions and learning activities that are intended to alleviate loneliness in this population. It points out key literature and also findings from our work that presents viewpoints of both individuals with SCI and SCI health care providers. And it also includes some practical tools.

So we have included in the educational curriculum things like validated measurement instruments to measure loneliness. Also some information and guidance on how to score and interpret the results when people use these tools. Another tool is a checklist of sorts that can help health care providers pick up on non-verbal cues or maybe indirect verbal cues that can be indicative of loneliness. And Marissa recently presented those findings at a spinal cord injury conference a few months ago. Marissa, maybe you can share some information about the loneliness cues?

MARISSA:

Yeah. So as Dr. LaVela was just mentioning, SCI providers identified potential cues to loneliness exhibited by individuals with SCI. So while direct verbal expression of statements such as, ‘I am lonely,’ are going to be the most straight forward, individuals often have difficulty with statements like that. So paying attention to word choice and tone and body language can be particularly important.

We also identified a few nonverbal cues. So we found that changes in physical health status. So potentially seeing if someone has an increased number of pressure wounds and also mental health indicator. So if an individual has depression or feeling hopeless. So those were also cues to loneliness. Other potential indicators is when an individual withdraws from their family or friends or self-isolate themselves within their home. Other cues are having poor lifestyle behaviors. So similar to what I had previously mentioned our research with lifestyle behaviors. So things like poor diet, but also we identified neglecting somebody's personal self-care or their environment, so such as their home.

And then interestingly, providers also mentioned both sides of the spectrum for health care utilization for these individuals. So some individuals who are experiencing loneliness may avoid their health care appointments or their needs where others are, whereas others actually fixated on health care. And that was through extending appointments or calling to carry out conversations to meet a social need.

I really want to highlight, though, that it's important to gather all information before assuming that any one of these factors are always loneliness cues.

To learn more about these loneliness cues and then the other content that Dr. LaVela was just mentioning, you can access the curriculum toolkit. And that is titled [Loneliness and Perceived Social Isolation Individuals Living with Spinal Cord Injuries and Disorders: Educational Curriculum for Health Care Professionals](https://www.cmc3.research.va.gov/Loneliness_and_Perceived_Social_Isolation_in_Individuals_Living_with_SCID.pdf). So that can be found a few ways. The first of which is on our VA Research Center's website. That web address is [www.cmc3.research.va.gov](file:///C%3A%5CUsers%5CVHAHINWirthM%5CAppData%5CLocal%5CMicrosoft%5CWindows%5CINetCache%5CContent.Outlook%5C3JKS60FW%5Cwww.cmc3.research.va.gov). Once on that website you can go to the research and quality improvement and then Toolkits tab. It's also going to be available on the [Facing Disability](https://facingdisability.com/resource/loneliness-and-perceived-social-isolation-in-individuals-living-with-spinal-cord-injuries-and-disorders-educational-curriculum-for-health-care-professionals) website or it's also going to be easily accessible on the show notes.

SHARON:

Well, thank you both for being on the podcast. This has been incredibly educational and I will be sure to link that resource your educational curriculum in the show notes that go along with the episode. So thanks again for being guests on the podcast.

MARISSA:

Thank you for having us and kind of giving us this opportunity to share the current research we've been working on.

DR. LAVELA:

Yeah, we appreciate the time.

SHARON:

This has been [INside the OUTcomes: A Rehabilitation Research Podcast](https://www.sralab.org/research/labs/cror/projects/inside-outcomes-rehabilitation-research-podcast). This podcast is supported by the National Institute on Disability, Independent Living, and Rehabilitation Research. I'm your host, Sharon Parmet, signing off.