

Module 11 – SCI 101 for Researchers

Psychological and social effects of an SCI

Spinal cord injury is a life-changing event that affects more than just physical functioning; it can disrupt many areas of life, including social connections, family roles, employment, marriages and relationships, and self-image.

Claudia Garofalo – I'd like researchers to know what it's like to live with SCI. That it is really, really difficult to be a person with SCI. Emotionally, of course physically. Financially, it's very difficult.

Sasha Rabchevsky – It affects so many different people at different stages immediately. Their lives change immediately and therefore it's a burden on themselves, obviously, but guess what, all those who are around them, and loved ones, they suffer as well, and for not just an instant moment, for a long time.

Gary – Having a spinal cord injury is about so much more than just the inability to walk. Just everything that able-bodied human being, be able to do and to accomplish is changed. So you're in a whole new world. It's pretty intense. It's very challenging.

Anita Kaiser – Living with a spinal cord injury is challenging, you know, it's a daily struggle. You're battling multiple secondary complications, accessibility issues, and inclusion in society. You know, many of us rely on others for assistance with our with our basic needs, and also on technology in order to be as independent as possible. And you know all of that takes toll on a person's mental health and their quality of life, so research that improves quality of life and enhances recovery and addresses these areas are very much needed.

Loss of Control

One challenge people with spinal cord injury face is the feeling of not being in control. People with spinal cord injury who are unable to move on their own must depend on others for many tasks.

They may also experience a change in their roles in the family. For example, a person who was the primary earner of money may transition to taking care of the home or family while their partner becomes the primary earner of income. If they also are unable to care for the home or family, they may feel guilt that their partner must carry the burden. These changes can create a feeling of loss of control over life.

Feelings of Vulnerability

Spinal cord injury can create a feeling of vulnerability.

Having to depend on help from others for the most basic of tasks, such as getting out of bed or dressing, can be scary or create fears of abandonment or being treated badly.

People with spinal cord injury may also be concerned about risks to their health, such as getting an infection, or breaking a bone during a transfer, or the failure of essential medical equipment.

Garret Frey – I do have anxiety, but that is when I am alone, when someone's not close by or near me. So like my mom at nighttime, um, I have her sleep next to me or someone that I feel comfortable with just in case something happened. you always wanna make sure that like, you have an Ambu bag close by you to get air quickly. Um, I don't really problem solve the ventilator right away unless you see like a circuit as disconnected, I like try to keep it simple. So like airway, you need to breathe first, um, that's always key.

Loss of Privacy

Spinal cord injury also creates a loss of privacy, especially for people who need help with tasks such as emptying bowels and bladder, bathing, and other personal tasks.

April - It's very difficult to have privacy, and it gets frustrating. And there's just things about you, just in your day-to-day life, when you're behind closed doors, that you don't necessarily want everybody in the world part of. But when you have a caregiver that has to come to you every day, whether it's just for a short period of time, or whether you have a caregiver that's with you all the time, it becomes impossible to hide some of those private details about yourself. And if you just think on a regular level, how invasive it would feel for someone to know every detail about you.

Lack of Confidence

People with spinal cord injury may feel afraid or unable to participate in certain activities because they are more difficult or feel different than they did before injury.

Gary - I guess the biggest challenge was because I lost my physical abilities, my confidence in doing things changed, and the way that I would approach someone or someone would approach me was very awkward. Also just trying to adjust to, you know, being a young man, and you know, you wanna go out, you wanna meet women or people your age and try to form some type of commonality. And you know, when you're in a wheelchair or when you have a spinal cord injury and your whole world changes, it's really hard to know what to say to someone and vice versa.

Social Isolation

Spinal cord injury can create feelings of isolation, because an SCI can affect a person's access to and ability to connect with peers, friends, family, and others in their communities.

People with spinal cord injury may have difficulty getting out into the community, particularly early on after injury. People with spinal cord injury may no longer be able to participate in activities they once shared with their loved ones.

Relationships with friends and loved ones may change after a spinal cord injury. Sexual dysfunction and lack of intimacy may also contribute to feelings of isolation and depression.

Many people with spinal cord injury have difficulty returning to work or school, which increases their isolation from others.

Financial Stress

Spinal cord injury can create financial stress. Acute medical care in the immediate aftermath of an SCI can be a costly and financially overwhelming expense.

Over the longer term, difficulty returning to work or finding employment can drastically reduce income. At the same time, an SCI leads to new ongoing expenses, such as medical supplies, equipment, and services from health care providers or assistants.

Mental Health

People with spinal cord injury may also experience depression, anxiety, post-traumatic stress disorder, or other mental health issues. These conditions may or may not be related to the event that caused spinal cord injury and its effects on life.

The physical and psychosocial effects that a person with SCI experiences also have implications for researchers. Next, we'll look at how understanding the lived experience can inform the kinds of questions that research asks, and how studies are designed to answer them.