

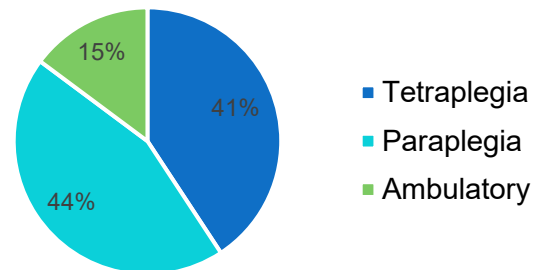
Community Peer Support Among Individuals Living with Spinal Cord Injury

This study examined the experience of peer support among 135 community-living individuals with SCI. We were interested in understanding how peer support relates to well-being following injury.

Demographics

Roughly half of participants were male, with an average age of 42. Most of the people surveyed (93.3%) resided in Canada or the US. The most common causes of injury reported were motor vehicle accidents, sport and recreation, falls, and medical reasons. As shown here, this study included participants with the diagnosis of tetraplegia, paraplegia, and ambulatory.

Injury Classification



Results

On average people were satisfied with the support they receive from their peers, reported very few complaints about their peer relationships, and rated having other people in their condition available to connect with them as very important. For example, one person said,

“The connection I have with my peers is difficult to put into words. There is a sense of unity we share in the fact that we know exactly what each of us is going through or experiencing, mostly as it relates to SCI-related issues (i.e., struggles with bladder and bowel management, inaccessibility, housing, employment, dating... etc). What I find most satisfying about the peer support I receive is that I never have to explain myself. My peers get it, they get me.”

Many people reported that the COVID-19 pandemic changed how much they value the peer support they receive, with one person expressing, “It’s shown me how important it is and how disruptive it is to lose that support” and yet another person saying, “I value it more, I didn’t realize how big a difference it made.”

Participants reported being in contact with their peer(s) on average 2-4 times a month, with roughly half reporting less frequent peer interaction since the onset of the COVID-19 pandemic.

We asked participants to tell us about the **satisfying aspects** of the support they receive from their peers. Relatability and understanding were the most commonly reported aspects, followed by receiving comfort and advice. To illustrate, one person wrote, “I love that they fully understand me and things I go through. We provide each other support and tips to help empower another.”

We also wanted to know what aspects of peer relationships are **most valuable**. Giving and receiving guidance, relatability, emotional support, comradeship, understanding, and humour were the most common responses. For example, one participant wrote, “...My SCI peers taught me to laugh, even in the most grim of circumstances.”

The main purpose of this study was to determine the extent to which peer support contributed to participants' well-being. We assessed peer support in 2 ways to address this question.

First, we considered whether the various things that people get from peer support (like practical information, emotional support) were related to their well-being.

Next, we asked about how satisfied people were with the support they receive.

We found that merely receiving peer support and the frequency of contact with one's peers **were not associated** with better well-being.

How did we measure well-being?

We asked about the experience of positive and negative emotions, symptoms of depression, feelings of loneliness, and reintegration into the community.

What is community reintegration?

Traumatic injuries create a number of challenges. Community reintegration is the degree to which individuals are able to return to normal social activities, such as recreation, movement within the community, and interactions with family and friends.

That said, how satisfied people were with the peer support they received **was related** to well-being: those who were more satisfied with the support were **less depressed, less lonely, happier, and more reintegrated** into their community.

We also looked at participants' relationships with their family and non-SCI friends. In general, participants felt very supported by their family and non-SCI friends and reported very few unsupportive responses from family and non-SCI friends. The most commonly reported challenges were a lack of understanding, difficulty relating, discussing

pain, and discussing the intimate aspects of having an SCI.

The quality of support from one's family and non-SCI friends **was not related** to more or less interaction with one's peers. That said, individuals who felt **less supported by their family and non-SCI friends** reported being **more satisfied with the support they receive from their peers**.

A NOTE FROM THE RESEARCHER

Thank you for participating in this study. We greatly appreciate your time and insight. We embarked on this study because the research on peer support is mixed – there is no clear relationship between receiving peer support and better well-being. This study contributed to science in that it suggests the inconsistent findings between peer support and well-being may be due to how researchers are asking the question. We hope this research will contribute to the SCI community by highlighting the need for follow-up with individuals receiving peer support to determine how the support is being perceived, for example, if the individual is satisfied with the support they are receiving.

If you are interested in participating in future studies conducted by our lab, please contact me, Joy McLeod, at joy.mcleod@carleton.ca.