

ARTICLE



Outcomes of peer mentorship for people living with spinal cord injury: perspectives from members of Canadian community-based SCI organizations

Shane N. Sweet^{1,2}✉, Lauren Hennig¹, Zhiyang Shi^{1,2}, Teren Clarke³, Haley Flaro⁴, Stephanie Hawley¹, Lee Schaefer⁵ and Heather L. Gainforth^{6,7}

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STUDY DESIGN: A generic qualitative design.

OBJECTIVES: To obtain a deeper understanding of the outcomes of spinal cord injury (SCI) peer mentorship programs delivered by community-based organizations.

SETTING: Peer mentorship programs of community-based SCI organizations

METHODS: We interviewed 36 individuals who shared their experiences of SCI peer mentorship from the perspective of a peer mentee, peer mentor, or family member of a peer mentee/mentor, or staff of SCI community-based organizations. Interview data were analyzed using an inductive thematic analysis approach.

RESULTS: Four overarching themes with sub-themes were identified. (1) Positive outcomes for mentees such as understanding, emotional outlet/psychological support, inspiration/hope, and belonging. (2) Positive outcomes for mentors such as gaining gratitude, confidence, pride, and personal growth. (3) Reciprocity in positive/negative outcomes for mentors and mentees, such as shared learning and a lack of connection. (4) Negative outcomes for mentors such as impact of negativity, emotional toll, and time/energy demands.

CONCLUSIONS: Peer mentorship programs delivered by community-based SCI organizations are important, impactful resources for individuals with SCI who engage in these programs. These results provide insights into the variety of positive and negative outcomes linked with these programs.

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INTRODUCTION

Peer mentorship programs for people living with spinal cord injury (SCI) have been made widely available across Canada [1]. Our team has defined peer mentorship as a peer interaction that aims to help individuals who share similar lived experiences adapt and/or thrive [2]. Peer mentorship programs delivered by community-based SCI organizations typically aim to help individuals with SCI adapt to living with a SCI and thrive with their new reality. These programs are often multi-purposed (e.g., focusing on rehabilitation and/or social reintegration), address various issues (e.g., improving health, teaching skills) and are delivered using different approaches (e.g., group, one-on-one). Individuals with SCI can be introduced to these programs while in rehabilitation or through community outreach and events organized by community-based organizations [3].

The multi-purposed approach to peer mentorship renders these programs difficult to evaluate and identify key outcomes. In a broad evaluation of Canadian SCI community-based organizations that offer peer mentorship programs, only 67% of community-based organizations systematically tracked outcomes [1]. Lack of resources and uncertainty about which outcomes to use were

identified as key barriers to evaluate community-based peer mentorship programs. In their scoping review, Barclay and Hilton highlighted that SCI peer mentorship studies assessed many outcomes with no consensus on which outcomes should be consistently measured in this setting [4]. There is evidently a lack of understanding on the outcomes most relevant in SCI peer mentorship context, and especially within programs delivered by community-based organizations.

Some SCI peer mentorship qualitative studies have hinted at key outcomes such as hope, acceptance, identity building, self-efficacy, quality of life, and participation in daily and social activities [5, 6]. However, when quantitatively exploring the impact of peer mentorship programs delivered by community organizations, only small to moderate effects were found on some of the identified outcomes including competence/self-efficacy, participation, and quality of life [7]. There has been some promise in controlled research-based interventions which have found moderate positive effects on self-efficacy, self-management skills, awareness of resources and services, and life satisfaction [8, 9]. There remains an important gap in our understanding of key

¹Department of Kinesiology and Physical Education, McGill University, Montreal, QC, Canada. ²Center for Interdisciplinary Research in Rehabilitation of Greater Montreal, Montreal, QC, Canada. ³Spinal Cord Injury Alberta, Edmonton, AB, Canada. ⁴Ability New Brunswick, Fredericton, NB, Canada. ⁵College of Kinesiology, University of Saskatchewan, Saskatchewan, SK, Canada. ⁶School of Health and Exercise Sciences, University of British Columbia – Okanagan, Kelowna, BC, Canada. ⁷International Collaboration on Repair Discoveries, University of British Columbia, Vancouver, BC, Canada. ✉email: shane.sweet@mcgill.ca

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outcomes of peer mentorship programs delivered by SCI community-based organizations.

Capturing a comprehensive picture of SCI peer mentorship outcomes within ‘real world’ peer mentorship programs is critical for optimal evaluation of these programs. Such a picture could provide community-based organizations with data highlighting the impact of their peer mentorship programs on people with SCI and help them obtain additional resources to support peer mentorship programs. The data can also help guide the process to identify the most important outcomes for the SCI context and inform the development of a community-based peer mentorship evaluation tool. Therefore, the purpose of this study was to obtain a deeper understanding of the outcomes of SCI peer mentorship programs delivered by community-based organizations. This qualitative study was led by the following research question: What are the outcomes of SCI peer mentorship programs delivered by community-based organizations?

METHODS

Research design

A community-university partnership was established between four provincial community-based SCI organizations and researchers from two universities [10, 11]. Using the IKT guiding principles for SCI research [12], members of the partnership were involved with the funding application, co-developing the research questions, and interpreting and disseminating the results. The research team consisted of directors of community-based SCI organizations with, collectively, over 25 years of experience (TC and HF), academic SCI researchers with qualitative research experience (SS and HG), a qualitative academic researcher (LS), and graduate students (LH, ZS, and SH). LH, a graduate student, was trained as a qualitative researcher under the supervision of LS and completed SCI educational modules prior to conducting the interviews. Team meetings were held throughout the research process (Appendix A).

We applied a generic qualitative design given the exploratory and descriptive nature of this study on the subjective experiences of individuals with peer mentorship programs [13, 14]. We adhered to a constructivist, interpretivist approach with a relativist ontology. Meaning, we positioned knowledge as being socially constructed and reality as relative to the individual and context. We did not attempt to find a transcendental “Truth” about SCI peer mentorship, but rather we aimed to illustrate the diverse experiences of individuals involved in SCI peer mentorship [15].

Participants

Using a purposive method, the partnered provincial community-based SCI organizations recruited participants through their data management system and/or direct contact. Eligible participants were adults, spoke English or French, and were not diagnosed with cognitive impairment. They either received peer mentorship (i.e., mentees), provided peer mentorship (i.e., mentors), be a family member of a mentee/mentor, or coordinated peer mentorship programs (i.e., staff with or without SCI) within the programs delivered by our partnered community-based SCI organizations. Participants self-reported whether they met or not each inclusion criteria when signing the consent form. Prior to the commencement of the interviews, the researcher doubly verified with the participants to confirm their eligibility.

Procedures

The Research Ethics Boards of McGill University and the University of British Columbia Okanagan approved this study. We collaborated with our partner organizations to identify eligible SCI peer mentors, mentees, and organizational staff. After obtaining informed consent, participants took part in a one-on-one interview. During the interviews, participants shared their experience with community-based SCI peer mentorship. We also invited mentors and mentees to refer family members who may have an interest in our study. Family members who consented to participate were also individually interviewed to discuss the impact of peer mentorship.

All interviews were semi-structured by following an interview guide (Appendix B) consisting of open-ended questions. The interview guide was co-designed with the community partners and pilot tested with lab members and a person with SCI prior to the start of the study. We did not

apply any theoretical frameworks when developing the interview guide. No adjustments were made to the interview guide following the test as it was found to be comprehensive and open to input from multiple perspectives. Each interview was 45–60 min long and was performed via phone or Skype because participants were recruited from four different provinces in Canada. All interviews were audio-recorded and transcribed verbatim while the organizations’ and participants’ names were replaced by pseudonyms. LH composed fieldnotes during and after the interviews.

Data analysis

Data were analyzed using a thematic analysis approach [16]. The graduate student (LH) was immersed in the data by reading and recalling the interviews repeatedly, and then extracted codes (i.e., meaningful portions of data relevant to the research questions) from the transcripts which were reviewed by SS. The codes were reviewed and grouped into themes and sub-themes by LH, SS, and a research assistant over two days. Next, six rounds of discussion were held between LH and SS to ensure that the codes cohered meaningfully within each theme and the definitions of the themes differed. All themes and sub-themes were developed inductively based on the data reported by participants and researchers’ interpretations. The codes, themes, and sub-themes were reviewed with community partners TC and HF, as the community-based critical friends. Their active involvement helped ensure the results were valid to the practice of our community partners [17, 18]. Therefore, multiple researchers were involved in the analysis, which ensured reliability and credibility. Important considerations, actions, and decision-making throughout the data collection and analysis were documented using an audit trail. This strategy enabled us to inspect and reflect on the research process [17]. We have opted not to consider data saturation for the analysis because it did not align with our constructivist, interpretivist research approach [19].

RESULTS

I was twenty-four when I got hurt...and very involved in a very superficial world. When I got hurt, obviously, that was over for me. I, basically, lost all sense of my image. I was never going to wear a skirt again, like that was it. [Then], at the hospital, I remember seeing this girl roll by. She was so beautiful, and she was wearing a skirt. I talked to her, and she was a [peer] counselor, but I didn’t know that. She took me shopping. I didn’t buy anything because I was horrified to buy anything. But, we went out, had a glass of wine, and hung out together. We got hit on by some guys. That I was like, ‘Wow’. I didn’t realize the impact of that [moment] until later in my life. (Melissa, staff, complete tetraplegia, had been a mentee and a mentor)

Peer mentorship can have a lasting positive impact on individuals with SCI and these positive experiences extend to those providing mentorship (i.e., peer mentors). Interview data ($N = 36$) from nine peer mentees, thirteen peer mentors, six family members, and eight staff were organized into four overarching themes (presented as headings)—Positive outcomes for mentees, Positive outcomes for mentors, Reciprocity, and Negative outcomes for mentors—and sub-themes, in italics (Fig. 1). Participants’ demographic and SCI-related information are presented in Table 1. Participants’ quotes supporting each sub-themes are presented below or in Table 2.

Positive outcomes for mentees

Participants emphasized the importance of feeling understood (*Understanding*) while living with SCI. Specifically, “it helps to know that somebody really understands what you’re going through... [especially when] people say, ‘Oh yeah, I understand.’ [but] How? You’re an able-bodied person. How could you possibly understand what I’m going through” (Valerie, mentee, complete tetraplegia). Therefore, SCI peer mentorship is about “being able to share with someone [with SCI]...it’s just something they understand. Whereas with other people, you kind of need to explain what your situation is or how you’re feeling, and they might not understand” (Linda, mentor, incomplete tetraplegia, had been a mentee).

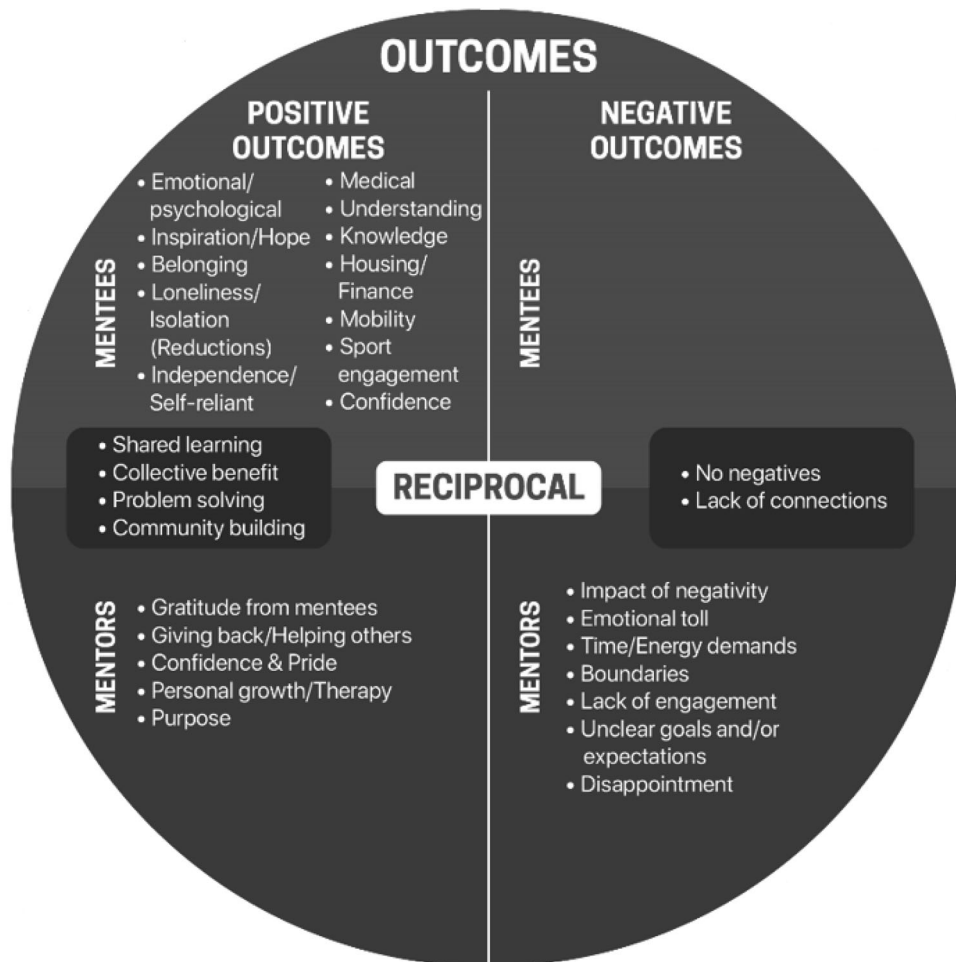


Fig. 1 Structure of the themes and sub-themes of SCI peer mentorship outcomes for mentors and mentees. Positive and negative outcomes are listed on the top half of the figure for mentees and on the bottom half for mentors. Reciprocal positive and negative outcomes are listed in the darker boxes in the middle of the figure.

From an emotional/psychological point of view, SCI peer mentorship serves as a source of *Inspiration and Hope* because mentors “pretty much showed me that there is life after. You can live a great life. And yeah, just because you’re in a chair—life still rolls on” (David, mentee, complete tetraplegia). It also helped reduce feelings of *Loneliness and Isolation* by “knowing that you’re not alone” (Melissa, staff, complete tetraplegia, previously a mentee and mentor). SCI peer mentees often tell Melissa “My doctor tells me that I’m a unicorn. There’s no one else like me” and Melissa typically responds that “[the type of SCI] is not unusual, but it could be for a doctor” to highlight that a mentee is not alone in their experience of SCI. Peer mentorship can serve as an *Emotional Outlet and Psychological Support* for people with SCI. Lisa, a family member, mentioned that “there’s a fine line between falling into a depression and trying to live day to day. Leo [Lisa’s partner] said that Leo’s mentor’s visits helped him [Leo] get out of that depression. Peer mentees also obtain a sense of *Belonging* in a community because it helps a person “stay involved. I guess to make new friends. Find a community... Just enjoying life better” (Sam, mentee, incomplete tetraplegia).

Tangible outcomes of SCI peer mentorship were also noted by participants. For one, SCI peer mentorship assisted mentees to navigate the *Medical Field* and healthcare system such as communicating and understanding healthcare professionals: “making sure that I’m speaking to the right person [healthcare professional]” (Jeff, mentee, complete tetraplegia). Participants indicated that SCI peer mentorship can help mentees regain *Independence/Self-reliance* as

highlighted by Kimberly (mentor, complete tetraplegia): “Positive outcomes are when they’re able to progress in life, and start managing things on their own”. Mentees also acquired *Knowledge* including tips and tricks. Without mentorship, “I’d still be probably struggling. It’s basic little tricks and tips. I’ve seen a lot of guys that they end up going back to their apartment or house, and struggle out because they don’t know how to transfer right” (David, mentee, complete tetraplegia). These tricks are important for various life domains such as *Housing and Financial Assistance*.

From a community engagement perspective, mentees reported experiencing enhancement in *Mobility* within the community such as assistance for transportation: “When I was looking for a vehicle, I asked him [the mentor], because he’s been driving for years, what should I watch for when picking out a vehicle” (Richard, mentee, complete tetraplegia). *Sport Engagement* was another way that SCI mentorship benefited mentees where James (mentee, incomplete tetraplegia, had been a mentor) mentioned:

The highlight would be when I got in that rugby chair. [My mentor] finally hounded me enough to actually get in it and to actually do it. And then, I mean, I wanted to spend as much time in the rugby chair as I can.

SCI peer mentorship supported individuals to find *Employment*. Paul (mentor, incomplete tetraplegia, previously a mentee) highlighted that “my first summer job in [city] was found for me by the [provincial organization], through the association’s

Table 1. Participant demographic and SCI-relevant information.

Category	Sub-category	Number of participants	Mean
Organization	Ontario	6	
	Alberta	10	
	British Columbia	12	
	New Brunswick	8	
Roles	Mentors (with SCI)	13 (13)	
	Mentees (with SCI)	9 (9)	
	Family/friend (with SCI)	6 (0)	
	Organization staff (with SCI)	8 (4)	
Interview method	Skype/appear.in	15	
	Telephone	21	
Age			47.4
Gender	Men	20	
	Women	16	
Ethnicity	White	31	
	Black/Indigenous/Asian	5	
Marital status	Common law/married	19	
	Single/divorced/separated	17	
Education (highest level)	High school	5	
	College	10	
	University	12	
	Post-Graduate	9	
Years in Program			7.1
(Only for mentees/mentors)	1–2	10	
	3–4	5	
	5+	7	
Number of PM interactions in the past year			8.3
	1–5	3	
	6–10	2	
Number of mentees (Mentors) ^a	1–9	5	
	10–19	2	
	20–100	4	
SCI type	100+	2	
	Paraplegia	10	
	Tetraplegia	16	
SCI completeness	Complete	12	
	Incomplete	14	
Mode of mobility	Walking (with walker)	1 (1)	
	Manual wheelchair	16	
	Power chair	8	
Asia classification	A	10	
	B	6	
	C	7	
	D	3	

^aSpecific numbers of mentees were not recalled by mentors.

contacts. [It was about] being aware of the potential job that would fit". As such, gaining the knowledge, tips and tricks can help mentees build *Self-confidence*, as Emily (mentee, incomplete tetraplegia) stated that peer mentorship "made me less worried and it gave me courage to move on and have my head up high".

Positive outcomes for mentors

Participants discussed how SCI peer mentorship benefited mentors by virtue of engaging in the mentoring process. From a personal attribute perspective, mentors reported gaining *Confidence and Pride*: "Obviously, it wasn't all from me, but I'd like to take a little bit of pride in knowing that I sort of got them to open up and not feel as bitter and angry as they did when they first got there" (Josh, mentor, complete tetraplegia). From mentoring, they reported developing a sense of *Purpose* ("I know Tom [participant's husband] has mentioned that before; it makes him feel like he has a purpose. He felt lost for a while"; Natalie, family) and experiencing *Personal Growth* ("It's a good healing thing for me as well. Every time I do a talk, I think: 'Well, maybe I could've talked about this or that a little more.' So you can grow on what you talk to people about"; Brian, mentor, complete tetraplegia).

Mentors got a sense of *Gratitude from Mentees* from the positive feedback they received for helping a fellow person living with SCI. Natalie (family) expressed the gratitude felt by her husband: "[He] was just so happy that he was able to answer all the questions. He had the biggest smile on his face. He was like 'I feel like I actually helped him'". Mentors also indicated enjoying *Giving Back by Helping Others*, as Kimberly (mentor, complete tetraplegia) expressed mentorship gives her "that drive and determination each day to go to work, and to help people, and to be there as a support to them. And it just feels good when you're able to help someone and be there for them".

Reciprocity

Participants reported outcomes that were beneficial for both mentees and mentors. As a result, there was a *Collective Benefit* where "even if you are positioning yourself as a mentor, and someone is kind of a role model and in a position of helping, you still derive an immense benefit, kind of reciprocally from the other person" (Donald, mentor, incomplete tetraplegia). Mentors and mentees also gained knowledge about living with SCI from each other through *Shared Learning*. Drawing on the multiplicity of experiences and perspectives, mentors and mentees improved their *Problem Solving Skills* by co-creating unique solutions. For mentees and mentors, *Community Building* was an important outcome: "There's a reality to say we are building an SCI community because we need each other" (Jeffrey, staff, complete tetraplegia, had been a mentee and a mentor).

Some participants reported having *No Negative Experiences or Outcomes*. However, a challenge in some mentorship relationships was a *Lack of Connection* between mentees and mentors, resulting in less than optimal mentorship experiences or even the discontinuation of mentorship.

Negative outcomes for peer mentors

The emotional commitment of providing peer mentorship could also have some negative outcomes as expressed by participants. They reported the *Emotional Toll* of mentorship:

"As a mentor, I'm still a person living with SCI, dealing with stuff every day. If I'm feeling kind of precarious about that, on top of that I'm dealing with someone who's also got a very serious issue...that can become difficult to manage emotionally" (Donald, mentor, incomplete tetraplegia)

The demands of peer mentorship can also force mentors to relieve their traumatic experiences while retelling their story when trying to support others. Further, the *Impact of Negativity* associated with difficult mentorship conversations/interactions also took a toll on mentors. Finally, participants noted feelings of *Disappointment* when expected outcomes were not attained, such as Donald (mentor, incomplete tetraplegia) who mentioned "I

Table 2. Themes, sub-themes, definitions, and quotes of outcomes of SCI peer mentorship.

<i>Sub-themes</i>	<i>Definitions</i>	<i>Quotes</i>
Positive outcomes for mentees		
Understanding	Feeling understood, having a sounding board, ease of interaction	"Well, when a friendly face [laughter] wheels up to your bedside and says, "Hello, I'm Sarah from a community-based organization, how are you doing?" I mean, you're desperate for visitors anyway when you're lying there. So a visitor who's been where you've been, it was just as I said, profound." – Mary (Mentee)
Inspiration and hope	Source of hope + inspiration	"He said he had an injury when he was young, and he was quadriplegic, I think. But at this stage, he was married, had kids, he was working, and he was still continuing to mentor other people. So, he never gave up in life. He worked hard. He was on a power chair and had no movement. He could control everything with his mouth on that chair. That was very inspiring." – Emily (Mentee)
Loneliness and isolation	Reducing feelings of loneliness	"Good, because you get to know people really care about you, and you get to know that you're not alone. That helps you to build your confidence, be optimistic, and believe in yourself no matter the situation." – Emily (Mentee)
Emotional/psychological	Emotional outlet/psychological support	"Absolutely. I do feel like it's had a positive impact. Even in the last year, he's even been more open. Where I thought he was as open as he could be before, it's almost like he's even more open now and more comfortable." – Natalie (Family)
Belonging	Sense of belonging in a (the SCI) community	"It gives you a great engagement in at least going along on activities or doing things with people who are similar to you, because you feel amongst friends." – Elizabeth (Family)
Medical field	Helping to navigate healthcare system, including identifying/seeking the right healthcare professional	"Erectile dysfunction and erectile consistency. So, it became more of a medical thing. And part of it is "Which doctor is that?" At first, I wasn't sure if it was an occupational therapy or a podiatrist issue, but he said, "No it's more of urology and these are the people." So, he helped me through that conversation." – Jeff (Mentee)
Independences/self reliance	Regaining independence; caring for oneself	"The word self-reliant becomes extremely important. The little things that we would never think about, attacks that we go through autonomically [autonomic functions such as heartrate, sweating] suddenly become extremely important because they're struggling and want the ability to do things again." – Jeffrey (Staff)
Knowledge	New information + building understanding of living with SCI	"When I was in the hospital not as an employee, when I was first injured, someone from a community-based organization came and helped me when I was there. I didn't have too much information on what to do after my injuries, so the information they provided to me helped me get into a place, helped me get the care I needed, the medical equipment that I needed. And I feel that that's necessary to people with a new SCI." – William (Staff)
Housing/financial assistance	Support finding resources for housing + finance assistance	"Yeah. Funding. Some random people have bank advice and stuff." – Sam (Mentee)
Mobility	Information and assistance for transport (ex. Driving) + travel (ex. Equipment)	"From me being a mentee, that was one of my first experiences. That guy that I mentioned, Jim, showed me you can drive and it's easy. I mean, not at first. It's just like learning how to drive." – David (Mentee)
Sport engagement	Trying sport as a new activity – team comraderies, physical fitness, competition	"Talked to a grade five class not long ago, and a little girl says, "Well, I have a disability." She says, "But my family never says I can play sports again." I gave her pamphlets, and I signed her a little autograph, and I said, "If you ever want to play, we have a kids' program all set up to play," and I gave her all the information. Sure enough, she made contact. It's just that people don't know what's out there for their kids, especially kids that are born with a disability. Some of them get sheltered, but now it's a great avenue for young people to get involved and the awareness that kids will get when I do those talks." – Adam (Mentor)
Employment	Support in finding employment (connections, positions, training, education)	"The most practical example of me benefiting from that contact was the fact that my first Summer job in Vancouver was found for me by the [community organization] ... and through the association contacts, being aware of the potential job that would fit. So it started very early." – Paul (Mentor)
Self-confidence	Source of building self confidence	"And that somehow helped me build on my confidence to know that, actually, I'm in a better condition than most people. Some people have much, much worse conditions. Yeah." – Emily (Mentee)
Positive outcomes for mentors		
Confidence & pride	Feeling of self-confidence; personal satisfaction	"Getting you out of your comfort zone will build that confidence, making you feel like you've actually conquered the struggles you thought you never could because if you're helping someone that means you've got through it" – Natalie, Family.
Purpose	Feeling of purposeful; becoming passionate about fulfilling a useful role	"I wanted to know what the community is about. I want to get involved more, and I want to do this for myself. I want to build resumes and build contacts too. So it was both." – Michael (staff)
Personal growth	Mentors process/cope with their own emotions through helping others	"If you try and encourage people, it gives you encouragement. As soon as you start trying to tell other people how they should overcome something, it makes you feel better too. So, I see a tremendous difference." – Elizabeth (Family)
Gratitude from mentees	Positive reinforcement for mentors	"The one example that happened to me was when I was seeing this fellow that was in rehab. He stayed there for probably more than six months, and was totally down and depressed. He was moved, after he got out of the hospital, up to northern [province], and then he came back to [a city] for one of our conferences that we had. He had his brother with him, and he said, "There's the guy that saved my life." Because I didn't give up on him, right? To hear that and know that impact that you've had on somebody when they say, "You've saved my life." How the heck did I do that? So that type of impact, that's my personal story." – Charles (Staff)

Table 2 continued

Sub-themes	Definitions	Quotes
Giving back/ helping others	Feeling of contribution; being of service for others facing issues of living life with SCI	"It's also very affirming to feel that you're being helpful to someone. For people living with SCI who are often in a position of being particular, with respect to physical functional limitations, of requesting assistance from other people—which can be disempowering. To be in a world of giving assistance to another person is very affirming." – Donald (Mentor)
Reciprocity		
Collective Benefit	Feeling that the relationship benefits both sides	"It's a fantastic experience to give back and to be helpful to someone who is in a position of need that you've probably experienced yourself, and you can get a lot out of it, as well." – Donald (Mentor)
Shared Learning	Both people gain knowledge from one another in the PM exchange	"And you're learning from their experience just as much as they're learning from you. If I can learn something from them, that's worth it." – David (Mentee)
Problem Solving Skills	Drawing on multiplicity of experiences and perspectives to source solutions and ideas for living with SCI	"Between my ideas and their ideas, we were always able to come up with solutions, or come up with plans, anything that I ever needed." – Josh (Mentor)
Community Building	Investment of individuals to support the building of a strong sense of community	"He got involved with a [non SCI organization] related volunteer organization, – I didn't care what volunteer organization he [volunteers] with, but he got involved as an active member of that organization. ... It shifted him from being about him to being about his community." – Kenneth (Mentor)
No negatives	Reporting no negative outcomes of peer mentorship	"I know that they would be an available resource, but I can't think of it off the top of my mind...any connection that we facilitated that's been negative, like from the get-go or that from either side, I should say, that the mentor or mentee have been like that was awful. I can't think of any example" – Kayla (Staff)
Lack of connection	Not able to connect with mentee/mentor	"That guy who came to see me, perfectly all right, acceptable guy...it just wasn't a good fit...that doesn't mean he wasn't ready to be a mentor. He wasn't ready to be my mentor" – Kenneth (Mentor)
Negative outcomes for mentors		
Emotional toll	Internalized effects of fulfilling the demands of PM (emotional commitment/investment)	"I expect for some people, there's a danger that they're going to get too involved...and he's quite emotional. The only thing I could see was that he would become upset or get too involved." – Elizabeth (Family) "The biggest one for me, that I experienced myself, is sort of a re-victimization. There's a sense of freedom or healing, especially after you've had a traumatic injury, of telling your story. Sharing your story is part of the grief and loss process. But then sometimes it's like reliving it over, and over again..." – Melissa (Staff)
Impact of negativity	Mentor efforts to mentally manage negative influences/mindsets of mentees after interaction	"I have heard through some other groups of peer support that it's kind of – excuse my language – but it turns out into more of bitch fest than something productive. I try to steer away from those groups or some of the drama that's associated with them." – Maria (Staff)
Disappointment	Outcomes did not meet expectations/needs of mentee and/or mentor	"I do feel guilty if their family members don't recover the way Tom recovered. There's that...I feel shitty, I feel awful, I wish I could tell them 'Keep doing what you're doing she/he will walk again, feed themselves...' But I can't, and it takes a toll on me" – Lisa (Family)
Time/energy demands	Requirements of mentor's time, energy, and "resources"	"Acute care, at times, requires daily or more often support. The time factor can be demanding on an unpaid volunteer" – Jeffrey (Staff) "Even if it's not difficult, it definitely requires energy. The mentorship –coaching sessions I did – even when they were positive, required a very substantial investment of energy" – Donald (Mentor)
Boundaries	Instances of having to assert boundaries to mediate needs that exceeded mentor's capacity/time/tolerance	"They [mentees] are so lonely in many cases. They will start knocking on your door day after day after day. This fellow with the scooter would come a mile away to our place in the afternoon, around 2 o'clock. That's usually when I put my feet up and when I get a knock on my door. I can't figure it out. 'How do you say no diplomatically?'. You got to be careful because it gets to a point where some people want just your friendship, not your advice." – Adam (Mentor)
Lack of engagement	Dealing with unmotivated mentees	"Both referrals didn't pan out simply because the other person canceled out. I was prepared to make a three-hour trip, and in both cases, the mentee decided very last minute they didn't want to do it" – Adam (Mentor) "Some people want it [mentorship] early on, others are so focused on their physical and their rehab early. All they're concentrating on is getting physically better, finding a place to live, transportation, housing, and finances. There's so much else going on that meeting up, talking, and socializing with a peer just isn't on their radar." – Charles (Staff)

Note: all names are pseudonyms, including within participant quotes. PM = peer mentorship

mean if you're working with someone who's facing really serious issues and you have the sense of not being able to help them as much as you would want, and [you will be] frustrated by that".

From a practical perspective, providing mentorship led to *Time/Energy Demands* where mentors invest their time and resources to provide mentorship. Participants also reported some difficulties establishing *Boundaries* between themselves and mentees: "A mentee that is calling me every single day gets to the point where it's too much or it's overbearing, then you'll have to say something, whether it's to one of my supervisors here or not"

(Joseph, mentor, complete paraplegia). Participants also reported a *Lack of Engagement* as feeling difficult or discouraging to work with unmotivated/uninterested mentees.

DISCUSSION

Our study aimed to garner an understanding of outcomes of SCI peer mentorship from multiple perspectives. Our results have identified SCI peer mentorship outcomes not previously researched and brought attention to negative outcomes experi-

enced by peer mentors. As such, this outcome-focused study highlighted the importance of looking at both positive and negative outcomes of mentees and mentors.

Similar to past studies, participants discussed outcomes such as hope, engagement in daily and social activities, and management of emotions [4, 6, 7]. Further, our study confirms that feelings of confidence (self-efficacy/competence) as a consistent outcome of SCI peer mentorship [4, 7, 8] and should be considered when evaluating SCI peer mentorship programs/interventions. However, other outcomes such as feeling understood have not been reported in previous SCI peer mentorship studies. Instead, the concept of understanding is discussed as a process/style of peer mentorship (e.g., mutuality of SCI experiences [7], providing empathy [20–22]). There maybe a missed opportunity to investigate the concept of understanding/feeling understood as an outcome in this context.

Feeling understood is a different concept from approaches or styles that support feeling understood [23]. Feeling understood can be defined as the belief “that another person ‘gets the facts right about me’ and also appreciates how the ‘self’ experiences the social world” (p. 2). This definition reflects our participants’ mentorship experiences and the experiences of others in different domains, including peer mentorship studies in mental health [24] and type 1 diabetes contexts [25]. Further, feeling understood maybe a proximal outcome of human interactions, such as in peer mentorship, that leads to broader outcomes. For example, university students reported greater life satisfaction on days they felt understood [26]. Similar findings maybe found in a SCI context, but the SCI peer mentorship literature has not embraced the notion of ‘feeling understood’ as an outcome. Our result suggests that greater emphasis can be placed on proximal/direct outcomes (e.g., understanding) rather than broader/indirect ones (e.g., quality of life).

A negative outcome that was reciprocal for both mentors and mentees was a lack of connection. Sharing the same disability may not be sufficient for high quality mentorship experiences [27] and little research exists on the important matching criteria for peer mentorship relationships [28]. Recently, Gainforth et al. described that matching characteristics should be more focused on interest and lived experience, which differs from traditional models matching on level of injury/sex [23]. As such, community-based SCI organization may need to consider matching criteria as a way to foster stronger connections between mentors and mentees.

Peer mentors also experience outcomes when engaging in peer mentorship [29]. In our study, personal growth, giving back, and an increase in self-confidence and pride were identified outcomes for mentors. Further, the reciprocal benefit of peer mentorship also assisted in co-learning problem-solving skills and building a sense of community. Our results also highlighted negative elements of peer mentorship for mentors. For one, discussions arose around boundaries and the friendship/non-friendship lines. The challenge of establishing boundaries is appearing more frequently in the peer mentorship literature [20]. Brown et al. highlighted that foster care peer support volunteers expressed concerns regarding boundaries, showing that this topic requires greater attention [30]. We may need to reach out to other professional care practices (e.g., psychologist) to learn how such boundaries are established in those contexts to provide support to SCI peer mentors.

Participants also highlighted the emotional toll and the impact of negativity that mentors feel from providing mentorship. One explanation is that mentors might be experiencing compassion stress/fatigue. Compassion stress/fatigue is an emotional outcome resulting from helping others who are in difficult situations. It has often been observed in nursing [31] and psychological professions [32]. Given mentors highlighted the potential emotional toll and the impact of reliving their SCI, mentorship programs need to be mindful about finding ways to support mentors, including helping

them identify early signs of compassion fatigue. The importance of providing this type of training for SCI peer mentors was recently highlighted by Hoffman et al. [33]. Community organizations and researchers may need to work together to better understand how to best develop training materials and strategies to support mentors experiencing compassion fatigue.

Limitations

All interviews were performed via phone or Skype due to the national scope of the research. Compared to face-to-face methods, breakdowns and misunderstandings in communication maybe more likely to arise in such distal interviews [34]. However, the interviewer LH had previous experience in conducting virtual interviews for other projects. We interviewed a wide range of individuals, including those who received, provided, or supported mentorship. However, we did not differentiate by province, mentorship role, time since engaged in peer mentorship. We also did not differentiate between hospital and community-based outcomes as participants were all community-dwelling individuals and were asked about the impact of peer mentorship in general. Few mentees reported negative outcomes of SCI peer mentorship which maybe because we did not interview people who stopped peer mentorship due to negative experiences. Thus, future research could interview individuals who stopped peer mentorship and determine if there are outcomes specific during rehabilitation and in the community.

CONCLUSION

This study provided an account of possible positive and negative outcomes of SCI peer mentorship programs delivered by community-based organizations. As such, these programs are an important resource for those directly or indirectly engaging in these programs. These results will inform our team’s goal to co-develop a community-friendly peer mentorship evaluation tool to effectively and accurately evaluate the impacts of SCI peer mentorship programs delivered by community-based organizations.

DATA AVAILABILITY

The datasets of the current study are available from the corresponding author on reasonable request.

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AUTHOR CONTRIBUTIONS

The research questions, procedures, and interview guides were co-constructed between the directors of two SCI Community organizations (TC, HF) and academic researchers (SS, LS, HG). ZS contributed to the writing of the manuscript.

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COMPETING INTERESTS

The authors declare no competing interests.

ETHICS APPROVAL

The Research Ethics Boards of McGill University and the University of British Columbia Okanagan approved this study. We certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research.

ADDITIONAL INFORMATION

Supplementary information The online version contains supplementary material available at <https://doi.org/10.1038/s41393-021-00725-2>.

Correspondence and requests for materials should be addressed to Shane N. Sweet.

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