

Identifying the outcomes of participating in peer mentorship for adults living with spinal cord injury: A qualitative meta-synthesis.

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### Abstract

**Objective:** Peer mentorship is a flagship program utilized by Canadian community-based spinal cord injury (SCI). Through connecting trained SCI peer mentors with fellow adults with SCI, these programs help adults adapt and thrive following their injury. The objective of this meta-synthesis was to work with SCI community organizations and to identify outcomes of participating in community- or rehabilitation-based peer mentorship programs using an integrated knowledge translation approach.

**Design:** A meta-synthesis of 21 qualitative peer-reviewed studies and 66 community documents was conducted.

**Main Outcome Measures:** A total of 87 outcomes of peer mentorship were identified.

**Results:** The outcomes of peer mentorship were grouped according to six higher-order themes: 1) Independence: enhanced self-sufficiency; 2) Personal growth: positive psychological changes; 3) Activities and participation: greater participation in activities and events; 4) Adaptation: adapting to life with disability; 5) Knowledge: obtaining new information, resources, and opportunities; and 6) Connection: developing and maintaining social relationship.

**Conclusion:** The positive nature of the identified outcomes suggests that participating in peer mentorship can promote improved health and quality of life for adults with SCI. Furthermore, the integrated knowledge translation approach helped identify outcomes previously not examined within SCI peer mentorship research, thus providing important insight for future research.

**Keywords:** integrated knowledge translation, meta-synthesis, spinal cord injury, outcomes, peer mentorship

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### **Introduction**

Following a spinal cord injury (SCI), individuals with SCI participate in hospital, rehabilitation, and community-based programs to help them adapt to their injury and thrive in terms of their overall health and quality of life (Boschen, Tonack, & Gargaro, 2003; Divanoglou & Georgiou, 2017). One of the resources available to help adults with SCI during their rehabilitation is peer mentorship, which can be defined as any peer interaction that aims to help individuals who share similar lived experiences adapt and/or thrive (Canadian Spinal Cord Injury Peer Mentorship Community-University Research Group, 2020). Peer mentorship is offered through programs that link peer mentors with fellow adults living with SCI and have demonstrated promising results (Divanoglou & Georgiou, 2017). Since a peer mentor is an individual who has lived experience (Veith, Sherman, Pelling & Yasui, 2006), they can provide unique empathetic understanding, advice, and emotional support as adults adjust, adapt and thrive following their injury (SCI BC, 2020).

SCI peer mentorship programs are often offered through community-based organizations (Shaw, Sweet, McBride, Adair, & Martin Ginis, 2019). In Canada specifically, these organizations facilitate programs that are multi-purposed (e.g., target rehabilitation, later stages of life), address a variety of issues (e.g., new skills, community participation), are multi-context (e.g., offered in hospital, online, or in the community), and use a variety of delivery methods (e.g., one-on-one, group). As a result of participating in peer mentorship programs, adults with SCI generally report positive experiences, personal development, increased social connections, and improvements in their overall health and well-being (e.g., Divanoglou & Georgiou, 2017; SCI Alberta, 2020; Veith et al., 2006). When asked

informally, some adults with SCI report that peer mentorship was the single most important and impactful part of their recovery and rehabilitation (SCI BC, 2020).

To provide this programming for adults with SCI, community-based organizations all over the world rely on a blend of funding from private, public, government, sponsorships, and membership contributions to offer their services (Shaw et al., 2019; Divanoglou, Tasiemski, Augutis, & Trok, 2017). Through this funding model, these organizations must demonstrate that participation in their programming leads to meaningful outcomes for adults with SCI in order to justify their current funding and secure funding for the future.

### **Tracking Outcomes of SCI Peer Mentorship**

Currently, within Canadian SCI community-based organizations, there are no standardized approaches for measuring and tracking the outcomes of SCI peer mentorship. Some formally document positive and negative outcomes through annual engagement surveys, others rely on anecdotal feedback from participants through informal conversations, and some do not evaluate their programs at all (Shaw et al., 2019). Part of the challenge faced by these organizations is that they do not have the developed evidence-based tools required to formally track the outcomes (Shaw et al., 2019). With an effective SCI peer mentorship evaluation tool, SCI organizations can provide an additional rationale for funding, improve services, and continue to enhance the lives of people with SCI through peer mentorship.

A number of academic researchers have examined the role of SCI peer mentorship in promoting outcomes for individuals. Using qualitative research method approaches, studies have linked participation in peer mentorship programs with community reintegration (Boschen, Tonack, & Gargaro, 2003), self-care (Divanoglou & Georgiou, 2017), identity (Hernandez, 2005), physical activity participation (Kerstin, Gabriele, & Richard, 2006), and leadership (Shaw, McBride, Casemore, & Martin Ginis, 2018). These results are consistent with the testimonials from adults with SCI who have participated in peer mentorship, as well

as the impressions of SCI community-based organizations who offer these programs (e.g., SCI BC, 2018). These research methodologies, however, do not provide SCI community-based organizations with tools they can use within their own organizations to quantitatively document outcomes, as well track changes over time.

Academic researchers have incorporated quantitative approaches to examine the role of SCI peer mentorship in promoting outcomes for individuals. These studies have used general research measures to assess broad concepts such as participation (e.g., Sweet et al., 2016) or quality of life (Sweet et al., 2018), but the results are inconsistent and the effects are small. For example, research looking at skill-based outcomes such as wheelchair training, has demonstrated that peer mentorship can effectively help adults improve or master new skills (e.g., Best, Miller, Huston, Routhier, & Eng, 2016). In terms of psychological outcomes, Sherman, DeVinney, and Sperling (2004) and Sweet, Noreau, Leblond, and Martin Ginis (2016) found that peer mentorship was weakly associated with life satisfaction, but a separate study found that was only for adults who had their SCI for 30+ years (Sweet et al., 2018). The examination of behavioural outcomes found inconsistent relationships between peer mentorship and social and activity participation in that peer mentorship was related to some aspects of participation, such as work or health, but not always (e.g., Sherman, DeVinney, & Sperling, 2004; Sweet, Noreau, Leblond, & Martin Ginis, 2016; Sweet et al., 2018).

The quantitative tools used to examine these outcomes may be the cause of the ambiguous results and weak effects. These quantitative tools may not capture the intricate and subtle details of these programs or may not be measuring the right outcomes, which could lead them to underestimate the role peer mentorship has in making a positive contribution to the lives of adults with SCI. These inconsistencies have been highlighted in a recent scoping review by Barclay and Hilton (2019) of peer-lead interventions following an SCI. In their review, they concluded that the field of peer mentorship in SCI is still in its

infancy and that a lack of consistency in the measures available among researchers is preventing the field from moving forward and conducting more rigorous and generalizable studies. Another issue highlighted by Barclay and Hilton is that the majority of the academic studies examining SCI peer interventions did not involve members of the SCI community in their design, data collection, interpretation, and dissemination of their results. Members of the SCI community, however, have asked to be actively involved in the research process in order to ensure that the end products (i.e., interventions, programs, conclusions) are relevant to their needs and experiences (Hammell, 2010). This lack of involvement in the research surrounding the outcomes of SCI peer mentorship is evidenced by the fact that the research designs often do not match the realities in which these programs are delivered in practice. For example, research-driven peer mentorship programs usually target one or two outcomes at a specific timepoint in the rehabilitation process (e.g., Best, Miller, Huston, Routhier, & Eng, 2016). Community-based peer mentorship programs, however, can be delivered at any timepoint, touch on a number of skills or behaviours, and do not necessarily target one specific outcome (Shaw et al., 2019).

Overall, there is still very little understanding of the potential broad effects of participating in peer mentorship and SCI community-based organizations, and academic researchers do not have the tools needed to adequately track and evaluate the outcomes of peer mentorship programs. SCI community-based organizations have identified addressing this issue as an urgent priority. Before tools can be developed, there is a need to determine the potential outcomes that may come from participating in SCI community-based peer mentorship programs and then to identify the most important or prevalent outcomes.

### **Present Study**

The overall objective of this study is to identify the potential outcomes for mentees of participating in peer mentorship for adults with SCI by conducting a qualitative meta-

synthesis of existing SCI peer mentorship research and grey literature (e.g., documents created outside formal publishing channels such as newsletters or annual reports) produced by SCI community organizations. This approach was selected since SCI peer mentorship research has primarily relied on qualitative designs (Barclay & Hilton, 2019), which allow exploration of experiences and associated outcomes. When identifying outcomes, these can be, but are not limited to, positive or negative psychological, behavioural, cognitive, affective, or other outcomes from research, community-based organization, or rehabilitation-based peer programs. Given that this is a community-driven project with the goal of addressing a community-identified need, an integrated knowledge translation (IKT) approach was used (CIHR, 2010). An IKT approach balances the ownership over the research between the SCI community and academic researchers, ensuring that the findings are applicable to the appropriate knowledge users, while ensuring methodological rigor from an academic perspective. For this project, researchers partnered with the directors of 5 Canadian community-based SCI organizations (Ability New Brunswick, Memo-Quebec, SCI Alberta, SCI British Columbia, SCI Ontario). This group has created a community-academic research team that examines SCI peer mentorship and has been awarded funding to conduct this research (McGill, 2017).

### **Materials and Methods**

The study's overall objective of identifying the potential outcomes for mentees of participating in peer mentorship for adults with SCI was achieved by synthesizing existing SCI peer mentorship research and grey literature in the form of SCI community organization documents through a qualitative thematic meta-synthesis. A qualitative meta-synthesis is appropriate for instances where the objective is to develop new knowledge based on an interpretive analysis of existing qualitative data (Zimmer, 2006). We chose to use a thematic synthesis approach (Thomas & Harden, 2008) which involves going beyond the original data

to identify overarching analytical themes. This approach was selected since it can be either data or theory driven, used in a variety of disciplines, and provides a structure for organizing the literature.

For this analysis, we followed the five-step procedures outlined by Williams and Shaw (2016). Specifically, we developed the goal of the synthesis (*Focus of the Meta-Synthesis*), then identified the relevant literature for the study (*Identifying Literature*) and evaluated the quality of each data source (*Establishing Quality*). Then we reviewed each source in order to identify the relevant findings (*Extracting the Data*) and finally analyzed and organized the findings (*Thematic Analysis*). Our data analysis and interpretations were guided by the six-phase approach for thematic analysis outlined by Braun and Clarke (2006). The phases involve: (1) getting familiar with the data, (2) generating initial codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes, and (6) producing a report. In line with an IKT approach, the academic and community members of the team met throughout each of the steps outlined above to discuss the results and determine the next steps.

### **Focus of the Meta-Synthesis**

The purpose of this synthesis was to identify the broad outcomes of participating in peer mentorship programs for adults with SCI (behavioural, psychological, etc.). In addition to reviewing the academic research on the outcomes of peer mentorship, we also examined grey literature in the form of community documents from our Canadian community organization partners that run peer mentorship programs. Our partners (Ability New Brunswick, Memo-Quebec, SCI Alberta, SCI British Columbia, SCI Ontario) have reports, access to primary data about the outcomes of their respective peer mentorship programs, and have unrivalled corporate knowledge about what is not typically captured in traditional research (Adams, Smart, & Huff, 2017). Additionally, although our community partners do

not represent all peer mentorship programs in Canada, their delivery methods and programs vary significantly and align with the different delivery contexts seen across the academic research, providing a broad perspective on the potential outcomes of participating.

Specifically, some programs focus on the acute and rehabilitation SCI stage (e.g., SCI Ontario), others are within SCI rehabilitation phases and in the community (e.g., SCI British Columbia, SCI Alberta, and MEMO-Qc), and others focus largely on community delivery (e.g., Ability New Brunswick). Their respective community documentation is important because its inclusion helps make a positive contribution to inquiry and practice since, in line with the IKT approach, it is relevant to the research questions (Adams, Smart, & Huff, 2017). Furthermore, making use of community documentation helped address the publication bias that is often associated with synthesis studies (Hopewell, McDonald, Clarke, & Egger, 2007) and lead to stronger conclusions (Levy & Williams, 2004).

The meta-synthesis included published academic literature, as well as community documents (e.g., newsletters, internal surveys, annual reports, testimonials) from our Canadian community partners (Ability New Brunswick, Memo-QC, SCI Alberta, SCI British Columbia, and SCI Ontario). This complimentary strategy helped ensure we adhered to the principles of the IKT approach and promoted a more comprehensive list of outcomes.

## **Identifying Literature**

**Identifying Academic Literature.** The CHIP tool (Shaw, 2010) was used to guide the academic search strategy by identifying the **c**ontext of this research (research question), **h**ow the methodological approach guided the selection of the studies (qualitative), the **i**ssue (peer mentorship), and the **p**opulation (adults with SCI). The search terms (listed in Table 1) were then created by the research team, which included academic researchers and community partners, through a series of group brainstorming exercises.

Once the search terms were created, M.R. met with the university librarian to validate the chosen strategy for this synthesis, confirm the appropriateness and exhaustiveness of the selected keywords, and identify the relevant databases to include in this search. On the recommendation of the librarian, Medline, PsycINFO, and Pubmed were searched in April 2018. This search yielded a total of 430 citations after duplicates were removed. The articles were screened for their relevancy to the research question and the inclusion/exclusion criteria based on their titles, their abstracts, then a full-text read. A PRISMA flowchart (Preferred Reporting Items for Systematic Reviews and Meta-Analysis) was used to record the decision-making processes (Moher, Liberati, Tetzlaff, & Altman, 2009). Studies were included in this review if they (1) examined SCI as the primary focus; (2) looked at peer mentorship broadly in the context of SCI (e.g., rehabilitation, community programs, paid, or volunteer); (3) involved an adult with SCI or someone closely related (mentors, mentees, family, caregivers, friends); (4) reported at least 1 outcome (of any type) of participating in peer mentorship; (5) examined adults aged 18+; (6) used qualitative data collection and analysis approaches; and (7) were available in English or French. Studies were excluded if they (1) did not examine an outcome of peer mentorship; (2) used a quantitative design; (3) participants were not 18+; or (4) the study did not examine adults with SCI. As seen in Figure 1, 21 articles were retained for the synthesis. A full list of the retained articles is provided in Table 2.

**Identifying Community Literature.** Community partners were contacted to provide the research team with access to their internal and public documentation related to their peer mentorship programs. They provided copies of their program evaluations, annual reports, budget reports, information brochures, testimonials, newsletters, magazines, webinars, PowerPoint presentations, and other community documents from 2015 to 2018 in either English or French. Based on the recommendations from our community partners, it was agreed that information that was three years or older (i.e., from before 2015) was not

necessarily still relevant to their current programming and only included if they felt it was still relevant. To reduce burden on the community partners, the research team independently accessed publicly available information (i.e., websites, social media posts). A total of 86 separate documents ranging from magazines, websites, annual reports, and testimonials varying in length between a couple of sentences to 76 pages were included in the analysis. Of the reviewed documents, 66 included at least once mention of an outcome related to SCI peer mentorship. A full list of the retained documents is provided in Supplementary Table A.

### **Establishing Quality**

**Establishing Quality of Academic Literature.** We followed the Critical Appraisal Skills Program (CASP) for qualitative research guidelines and applied the standardized appraisal developed by Feder and colleagues (Feder, Hutson, Ramsay, & Taket, 2006). The guidelines consist of 8 questions about the quality of the studies, the appropriateness of the methodology, the rigor of the analyses, and the clarity of the results (e.g., “Was the data analysis sufficiently rigorous?”). Each question is scored on 3 points (1 – weak, 2 – moderate, 3 – strong), for a maximum score of 24. A weak score indicates that the article offered little to no information about the particular question, a moderate score suggests that the article provided some justification for the question, but did not fully elaborate, and a strong score supports that the article provided a full and extensive justification for the question. For the purposes of the present study, the 21 articles were scored independently by M.R. and Z.S., and then an average of their ratings were used to calculate the mean CASP score (see Table 2). CASP scores should not be used to exclude articles (Sandelowski, Barroso, & Voils, 2007), but to provide an overall indication of the quality of the studies included in the synthesis. For the 21 articles in this study, the mean CASP score was 21.02 (SD = 2.15).

**Establishing Quality of Community Literature.** To establish the credibility of the literature provided by the community partners, we followed Adams, Smart, & Huff's (2017)

guidelines for working with grey literature in systematic reviews. According to their guidelines, the quality of grey literature should be assessed based on outlet control and source expertise. Outlet control focuses on the extent the content is produced and edited with explicit knowledge creation criteria, while source expertise is concerned with the extent the author can be determined and the authority of the content creator is validated. Sources are given a rating of significant (1<sup>st</sup>), moderate (2<sup>nd</sup>), and low (3<sup>rd</sup>). A significant rating is given to any grey literature where both outlet control and source expertise can be confirmed, such as books, book chapters, or government reports. Low ratings cover literature where neither can be confirmed, such as anonymous web posts (twitter, blogs), letters, or catalogues. Since these classifications can often be ambiguous, in instances where the source expertise is confirmed but outlet control is not, a moderate rating is given. For the purposes of this review, since the documents were all written by our community partners or their membership, the documents were given a rating of moderate.

### **Extracting the Data**

In the academic literature, all text under the results or findings section within the study abstract or main manuscript was analyzed (Thomas & Harden, 2008). Using both direct quotes from participants, as well as themes and interpretations identified by the researchers has the additional benefit of allowing factors that were not analyzed in the original studies to be included in this synthesis (Williams & Shaw, 2016). Since the documents provided by the community partners did not follow a consistent format, they were analyzed line by line, in their entirety.

The data was extracted and NVivo 11 (QSR International Pty Ltd) was used to facilitate generation of the initial codes. To increase the rigour of this process (e.g., Fromme, Hebert, & Carrese, 2004), authors M.R. and Z.S independently coded the 21 academic articles and 66 community documents for outcomes of peer mentorship, and then resolved

any duplications or disagreements through discussion. The operational definition of “outcomes” was intentionally broad and included “any positive or negative behavioural, psychological, cognitive, emotional, biological, or other, outcome associated with participating in SCI peer mentorship”. Altogether, the independent coding and subsequent discussions took each author approximately 30 hours and generated a total of 615 coded statements (i.e., outcomes). Some examples include “increased independence and self-reliance”, “ability to cope with SCI”, “getting involved in recreational activities”.

Once these data were extracted, we no longer distinguished between the sources of the data (i.e., academic versus community) and looked for similarities and differences in order to group the codes together into descriptive themes, representing unique outcomes of participating in peer mentorship. For example, similar codes such as “increased confidence”, “knowing that I am capable of much more”, and “development of a ‘can-do’ attitude” were all grouped under the outcome theme called “confidence”. This step resulted in the generation of 128 unique themes, representing an initial finding of 128 unique outcomes of participating in peer mentorship programs for adults with SCI (~10 hours). The data that support the findings of this study are available from the corresponding author, upon reasonable request.

### **Thematic Analysis**

Phases 1, 2, and 3 of Braun and Clarke's (2006) six-phase analytical approach were conducted alongside previous steps of the meta-synthesis. Specifically, we familiarized ourselves with the data while assessing the quality (Phase 1), we generated the initial codes when we extracted the data (Phase 2), and we searched for the themes when we grouped the codes together into unique outcomes of participating in SCI peer mentorship (Phase 3). In Phase 4, we reviewed the themes and through interpretation and conceptual synthesis of the data, M.R. and Z.S. grouped the 128 outcomes into 17 higher-order themes and 29 sub-themes over approximately 7 hours of discussion. In Phase 5, we engaged in a series of

discussions and meetings (approximately 30 hours) with the entire team to ensure consensus in the structure of the overarching themes and sub-themes, as well as define and name the themes. Refinements were made until the themes adequately encompassed all of the available data. The objective was to move beyond the data and create a greater understanding of the outcomes of peer mentorship for adults with SCI. We utilized a constant comparison method (Barnett-Page & Thomas, 2009), which involves a continuous examination of the codes and raw data to ensure that the themes capture the original data and there are no redundancies. Through these discussions, the data were reduced to 87 unique outcomes of participating in SCI peer mentorship, which were divided among 6 higher-order themes and 18 sub-themes. Finally, in Phase 6, we prepared a visual representation of the results, as well as a written summary in the form of this manuscript.

The community partners were not explicitly involved in Phases 1 – 3 of the thematic analysis, but were instead provided with regular updates about the status of the project (e.g., sent a list of the retained articles). This decision was made to help reduce burden on community partners given that Phases 1 – 3 would require an extensive time commitment, with minimal direct benefit for their organization. In Phases 4 – 6, the academic and community members of the team worked closely together during a series of recurring meetings to discuss and improve the interpretation of the findings, as well as determine how to visually represent the results. This approach enabled discussions and disagreements among members and provided insights to refine the themes (Barbour, 2001). By using an IKT approach for the thematic analysis, we helped ensure that the themes and interpretations were consistent with the language and vocabulary used within our community partner organizations. Thus, ensuring that these results will be meaningful and relevant to the community who will directly benefit from the results of this research.

## **Results**

The six higher-order themes and their sub-themes are presented in Figure 2 and summarized below. The themes are presented in alphabetical order and the summaries include direct quotes from the literatures, as well as general interpretations and paraphrasing. Please note that the reference number accompanying the quotes from community documents refer to the relevant numbers listed in Supplementary Table A. The complete list of 87 outcomes and their respective definitions are in Supplementary Table B.

### **Adaptation**

The first higher-order theme represents all outcomes related to adapting to life with an SCI. The outcomes were divided into two separate sub-themes: *adapting practice* and *skills*. *Adapting practice* focused on the changes and adjustments someone made to their new life with a SCI such as reintegrating back into society, adjusting to physical barriers, and overcoming challenges and obstacles. For example, participating in peer mentorship programs gave them a “better ability to navigate physical barriers when living with SCI (e.g. going on vacation, getting in and out of cars, driving, etc.) and the challenges it presents” (SCI Alberta, Ref. #31). The sub-theme of *skills* touched upon the ability to do something well and included general skills, as well as specific wheelchair-related, living-related, time management-related, support staff management-related, coping-related, and problem-related skills. Adults with SCI reported that peer mentors showed them “how techniques should be done, but also the range of skills and techniques that actually can be mastered in a wheelchair” (Standal & Jespersen, 2008, p. 217) and that it helped them “be able to learn to cope with [their] new condition in life” (Beauchamp et al., 2016, p. 1888).

### **Connection**

The second higher-order theme consisted of the outcomes related to the relationships between individuals living with SCI and others. Three sub-themes were identified: *general support*, *with others*, and *with those who understand*. The first sub-theme included a general

feeling of being supported (“knowing someone is there”; SCI BC, Ref. #41), emotional support (“emotional support from peers, both in-person and online, was particularly important immediately following their injuries”; O’Reilly, Rose, & Dalal, 2014, p. 182), goal support (“prompting me and pushing me along to reach my goals”; Houlihan et al., 2016, p. 1690), and comfort from others (“felt comfortable showing outward displays of emotion in the presence of mentors”; Veith, Sherman, Pellino, & Yasui, 2006, p. 295). The second sub-theme referred to the connections that individuals build (“establishment of new relationships”; Hernandez, 2005, p. 127) or maintain (“a long-term relationship with someone”; SCI BC, Ref. #45) with other people around them such as friends (“I’ve met new SCIs old friends and new friends in the SCI community”; SCI BC, Ref. #44) and family (“[improved] family functioning”; SCI BC, Ref. #45). Individuals with SCI reported “meeting new people” (SCI BC, Ref. #45) and “building and expand social networks” (Memo Quebec, Ref. #7) through peer mentorship. In addition, they reported reduced isolation (“I don’t feel like isolating”; SCI BC, Ref. #45) and a sense of belonging (“I belong to a community now”; SCI BC, Ref. #45). The last sub-theme, connection *with those who understand*, referred to a unique type of support that comes only from someone else who is in the same position. For example, individuals with SCI noted: “through the peer program I’ve connected with people who understand me in a way that nobody else really does” (SCI BC, Ref. #45). They received “great advice from people who have actually been through it” (SCI Ontario, Ref. #65), “normalization of new life situation and physical experiences” (SCI Alberta, Ref. #23), and opportunities to “share common experiences” (Hernandez, 2005, p. 127) from the interactions with peer mentors.

## **Growth**

A number of outcomes touched upon the psychological processes that help individuals thrive in the third higher-order theme, which we labelled “growth”, and this was

divided into six sub-themes. Two sub-themes included outcomes that were related to feelings and emotions. One referred to *future-oriented feelings* and included optimism and hope (“just gives you a little bit of hope and a little bit of feeling of security that, you know, hell, he made it through, and there’s no reason why I can’t do the same”; Veith et al., 2006, p. 292). The other included *present feelings and emotions* such as having a positive attitude, pride (“very proud of myself”; Memo Quebec, Ref. #9), dignity, happiness, enjoyment (“being able to enjoy activities that they always liked”; Divanoglou & Georgiou, 2017, p. 231), satisfaction, and reduced negative feelings, fear (“the more I learned, the less scared I got”; Veith et al., 2006, p. 291), and frustrations (“fewer daily frustrations”; SCI Alberta, Ref. #23). Another sub-theme included a change in *outlook and adjustment*, which included feelings of acceptance of a difficult situation (“come to terms mentally with what I was going through”; SCI Ontario, Ref. #65), new perspectives, reframing one’s thinking (“realistic in understanding what you have, and how you’re going to work with what you have”; Beauchamp et al., 2016, p. 1887), resilience in recovering from difficult situation, appreciation for experiences, and effectively coping with difficult situations. We also identified a sub-theme that encompassed perceptions related to one’s *identity* and their recognition of their potential and qualities. This included rebuilding one’s concept of who they are through identity formation, self-discovery, and discovering new purposes or meanings for their life (“it gave my life meaning”; O’Reilly, Rose, & Dalal, 2014, p. 183). We also identified a *well-being* sub-theme that included outcomes related to mental health (“emotionally it helps me stay healthy because other peers touch my life positively and I hope I do for them”; SCI BC, Ref. #44), general well-being, quality of life, vitality, reduced stress (“when I get stressed about my injury I know I can reach out to a peer”; SCI BC, Ref. #44), reduced depression, and reduced vitality. Finally, a *motivation* sub-theme was defined as adults with SCI’s desire to do something. They reported feeling inspired (“seeing somebody

in the same shoes doing it, was what made it for me. That was... it was proof”; Beauchamp et al., 2016, p. 1888), encouraged, wanting to help, empowered (he “empowered me... [and helped me realize that] that it’s OK to be upset and all that type of stuff, but it’s still... you know, life really did go on”; Beauchamp et al., 2016, p. 1890), persevered, motivation, and that they had support for their goals.

### **Independence**

The fourth higher-order theme represented outcomes related to becoming self-reliant and independent. Many results came out in support of the higher-order and sub-theme *independence*. For example, someone indicated that because of peer mentorship programs, they “realize[d] how independent they could still be, regardless of having a SCI” (Shaw et al., 2018, p. 136) or they reported “achieving independence” (SCI Ontario, Ref. #63) and “distancing [them]selves from the healthcare system to take back [their] own bodies and minds” (Standal & Jespersen, 2008, p. 220). An additional sub-theme revolved around the concept of *capability* which captures outcomes of self-efficacy (“recognized my own strengths and ability”; Ability NB, Ref. #2), confidence (“confidence to again venture out into the world”; Barclay et al., 2015, p. 7), and belief of potential (“awareness of individual potential”; Ability NB, Ref. #3). Participating in peer mentorship also results in adults with SCI reporting that they were able to *demonstrate their independence* through increased ability (“improving functioning abilities”; SCI Alberta, Ref. #23) and control (“take greater control over various important aspects of their lives”; Boschen et al., 2003, p. 161).

### **Knowledge**

The fifth higher-order theme touched upon gaining new information or accessing information and was divided into two sub-themes: *new information* and *opportunities and resources*. Knowledge about *new information* included everything from travel information (“I got a chance to talk to people who have traveled so much, and who have had such wonderful

experiences, despite being in a wheelchair and despite a disability, despite having lot of limitations”; SCI BC, Ref. #40), being healthy (“clearer understanding of how to maintain health and wellness post-SCI”; SCI Alberta, Ref. #30), nutrition health, bladder self-care, spasms, sexual functioning, pressure ulcers, government support (“information and advice about resources available in the community to help them deal with health, employment, educational, housing, recreational, or transportation needs”; Balcazar et al., 2011, p. 7), general knowledge, strategies for finding new information, and online information. The *opportunities and resources* sub-theme involved accessing general resources, and/or resources available online, in the community (“be more aware of supports and services available in the community”; SCI BC, Ref. #45), for living needs (“information and advice about resources available in the community to help them deal with health, employment, educational, housing, recreational, or transportation needs”; Balcazar et al., 2011, p. 7), and to contact key people available to adults with SCI (people resources).

### **Participation**

The final higher-order theme represented the outcomes in terms of participation in daily and social activities of individuals with SCI. Two sub-themes were identified, namely *health and recreational activities* and *community involvement*. Within *health and recreational activities*, engagement in new activities was identified among individuals who participated in peer mentorship programs. For example, individuals “have participated in such things like sailing” (SCI BC, Ref. #44) or “healthy cooking classes” (SCI Ontario, Ref. #65) through the opportunities introduced by peer mentors (“through effective role modelling his mentor introduced him to new activities” Beauchamp et al., 2016, p. 1890). In addition, peer mentorship helped promote their participation in physical activities, including sports (“reconnected me back to sports” and “sledge hockey”; SCI BC, Ref. #44) and exercise (“increase physical activity” Kerstin et al., 2006, p. 486). Within the *community involvement*

sub-theme, peer mentors offered social opportunities and helped mentees get involved in community. Individuals with SCI reported being more socially active (“I’ve been out doing a lot of things with different people in the community and that wouldn’t have happened without the peer group”; SCI BC, Ref. #47) and having “greater engagement in various life pursuits” (Beauchamp et al., 2016, p. 1884). They also reported greater participation in community events and activities (“increased community participation”; Ability NB, Ref. #3), such as “seeing parks and museums” (SCI BC, Ref. #44) and “increased involvement of volunteers” (SCI BC, Ref. #45). In addition, peer mentors helped “facilitate return to education” (SCI Alberta, Ref. #30) and provided “unexpected employment opportunities” (Hernandez, 2005, p. 128) to mentees.

### **Discussion**

Through this qualitative meta-synthesis, we used an IKT approach to analyze and summarize the findings of 21 peer-reviewed studies and 66 community documents to identify the potential outcomes of participating in peer mentorship programs for adults with SCI. The results yielded 87 unique outcomes that were divided into 6 overarching themes and 18 sub-themes. The meta-synthesis demonstrates the breadth of outcomes related to SCI peer mentorship and provides a comprehensive look at how such programs can help adults with SCI adapt, thrive, and improve their overall health and well-being, through many avenues.

The IKT approach and subsequent integration of community documents resulted in an exhaustive list of outcomes in this synthesis. A number of outcomes were found within both academic and community resources (see Supplementary Table B), such as independence, self-efficacy, confidence, optimism, physical activity, new activities, wheelchair skills, and coping. However, some outcomes were only found within the community partner resources such as self-esteem, pride, dignity, resilience, appreciation, reintegration, comfort from others, and challenges. These findings support that adults with SCI who participate in SCI

community-based peer mentorship programs are experiencing outcomes that the SCI peer mentorship academic research is not yet examining, which may contribute to the inconsistencies between the academic literature and experiences of members of the SCI community (e.g., Sweet et al., 2016). The identification of these additional outcomes is important since they improve our understanding of the potential of peer mentorship and were identified and named using the language of those who have experienced them first-hand – members of the SCI community. Thus, these outcomes are directly relevant to the experiences of adults with SCI and the organizations that serve them (Hammell, 2010).

Although we sought to identify any positive or negative cognitive, behavioural, and psychological outcomes of participating in peer mentorship, adults with SCI typically reported experiencing increased positive outcomes of their peer mentorship experience (Veith et al., 2006). In instances where negative outcomes, such as depression or anxiety, were discussed, peer mentorship was seen as a tool or opportunity to help reduce instances/symptoms of those negative outcomes. These results are consistent with the objectives of community-based organization peer mentorship programs in that they are designed to promote adaptation, thriving, connections, and independence for adults living with SCI. It should be noted, however, that only three of the five community organizations involved in this study have a formal tracking process for negative or unintended outcomes associated with peer mentorship (Shaw et al., 2019) and that, generally, researchers and community members are reluctant to discuss the negative sides of peer mentorship (Standal, 2011). Research examining peer mentorship in other rehabilitation settings has found mentees had negative experiences with peer mentorship when there was a mismatch between the mentee and mentor in terms of their personality, ages, experiences, or values (Embuldeniya et al., 2013). Another related issue is that the academic research and community organizations have typically emphasized mentees' experiences with peer mentorship and have dedicated

less attention and resources to the mentors. Findings from other fields suggest that being a peer mentor may sometimes lead to negative outcomes such as burnout (e.g., Fong, 2016). Therefore, the results of this study should be interpreted with the perspective that more negative outcomes may have been identified if adults with SCI had additional formal avenues for reporting them and were encouraged to discuss them in qualitative studies, or if outcomes for peer mentors were also examined in the context of this study.

Of the six higher-order themes, independence was the only outcome that was also labelled as a sub-theme and a higher-order theme. Independence is noteworthy because it was consistently found to be woven through the other outcomes that were found. Although the purpose of this study was not to examine the relationship between outcomes, we observed during our data analyses that through participating in peer mentorship, adults with SCI reported increases in a number of outcomes that were ultimately aimed at increasing their own independence following their SCI. This overarching need for independence is consistent with the findings from other fields of SCI research (Whalley, 2007). Specifically, the ability to resume control and responsibility of your own life, taking control of your care as much as possible, and regaining freedom is essential for improving quality of life in adults with SCI (Hammell, 2004). Future work may need to examine the interrelationships between these outcomes and determine whether some outcomes result directly from participating in peer mentorship, while others occur later once these direct outcomes have occurred. For example, improvements in skill-related outcomes may be a necessary precedent to feelings of self-reliance and/or independence.

While this study found that peer mentors help mentees adapt, connect, and participate amongst an assortment of other outcomes, these findings were generated using data obtained from five independent community organizations and 21 academic studies. The five organizations all have unique peer mentor training programs (Shaw et al., 2019) that could

impact the type of support peer mentors provide to mentees, as well as the type of outcomes they target. For example, if an organization's training program places greater value on a specific outcome like social participation, their peer mentors may be more prone to influencing outcomes related to the theme of "connection" (e.g., connection with others) as opposed to "knowledge" or "independence". Mentor's ability to effectively influence specific outcomes warrants further research. The types of outcomes a program may attempt to improve can also differ depending on the stage of life of the participant. Specifically, programs involving newly injured adults might try to examine outcomes associated with "growth", "independence", and "adaptation" instead of "participation" or "connection". Organizing SCI peer mentorship outcomes based on organization was beyond the scope of this study; however, examining how the content and structure of specific peer mentor training and program impacts a mentor's ability to effectively influence specific outcomes warrants further research.

### **Limitations**

A limitation of meta-syntheses is that the studies included as part of the academic literature use a variety of different methodological approaches and epistemological stances, which would influence the results that were reported. Additionally, although the search terms used for this study aimed to be exhaustive, it is possible some studies were missed if peer mentorship was not explicitly highlighted in the title or abstract of the study. Further, the results represent a synthesis of the results of other studies, and not the raw data from those studies. Specific to this study, we only analyzed data (both academic and community) that was available in English and French. For the academic literature, we only examined peer-reviewed articles which means that we may have missed relevant books or dissertations. For the community literature, we made use of the data from five Canadian community SCI organizations and did not examine community organizations outside of Canada. Finally, two

of the researchers involved in the analysis are Canadian and either work with persons with SCI or have lived experience of having a SCI. These experiences could be seen as biases in naming themes, but they are also critical in ensuring that our themes are consistent with how peer mentorship is experienced in the real world.

### **Future Research**

The expansive list of outcomes of SCI peer mentorship identified in this meta-synthesis highlights the complexity of using a single measure to evaluate the effectiveness of peer mentorship. Our review also draws attention to the challenge of training peer mentors to be capable of providing such a vast array of different types of support. When creating tools to measure the outcomes of peer mentorship, it is important to consider the unique characteristics of each program. This suggests that before evidence-based evaluation tools can be created there is a need to identify the most pertinent, versatile, and important outcomes in order to develop a common reference point. Subsequently, measurement tools can be developed with the direct help and input from members of the SCI community to ensure their applicability and encourage their uptake within the community.

(6923 words)

### **Declaration of interest statement**

The authors report no conflict of interest.

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