

ARTICLE



A mixed-methods study exploring and comparing the experiences of people who sustained a spinal cord injury earlier versus later in life

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STUDY DESIGN: Mixed-methods.

OBJECTIVES: (1) To explore psychosocial and quality of life outcomes between those injured early versus later in life, and (2) to explore their post-injury experiences.

SETTING: GF Strong Rehabilitation Centre, Vancouver, Canada.

METHODS: For this community-based study, we recruited individuals with SCI (>55 years of age) who were either injured between the ages of 15–30 ($n = 15$) or after the age of 50 ($n = 15$). We collected quantitative data about participants' sociodemographics and participants completed standardised questionnaires assessing personal factors, environmental factors, life habits, and quality of life. An independent samples t test was performed for continuous variables and the Chi-square test was conducted for the categorical variables. Qualitative data were collected via semi-structured interviews. Thematic content analysis was performed on the interview transcripts.

RESULTS: We found no statistically significant differences between the two groups on any of the psychosocial outcomes. However, those injured later in life were significantly more likely to be female, have a higher income, and live in residential care. We identified three main qualitative themes that were consistent across the two groups: 'dealing with health and changes in occupation', 'enacting interdependence', and 'living in the community'. Some sub-themes varied between groups.

CONCLUSIONS: To facilitate better rehabilitation, clinicians need to be aware of disparities among people with SCI relating to age of injury. Across age cohorts, it is important to increase independence, provide greater support when entering or returning to the workforce, and reduce societal stigma.

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INTRODUCTION

With the epidemiology of spinal cord injury (SCI) fluctuating over time, it is important to explore the evolving patterns. Historically, most individuals experiencing SCI were younger males [1]. However, between the 1970s and 2014, the average age of injury has increased from 28.7 to 42.2 years in the United States [1, 2]. The increased average age can be attributed to various factors including improvements in public safety, an aging population, and a shift in aetiology [3, 4]. Despite advances in acute medical treatment and continued care reducing patient mortality, people with an SCI still frequently experience significant psychosocial and physical sequelae including depression, fatigue, neuropathic pain, and pressure sores [5].

Accompanying an increase in average age, a bimodal distribution of the age of injury appears to be developing with peaks in the 15–29 and 45–49 age categories [2, 6]. A growing body of evidence suggests that there are many differences between these

two populations including the mechanism of injury, sex of those injured, and level of injury [1, 2, 4]. Previously, SCI was more common in younger men who experienced it through high impact aetiologies such as motor vehicle collisions or diving accidents. While this is still the primary cause in the younger age bracket, falls have become a main cause in the older age bracket [3]. This transition and diversification of causes help explain an increased incidence in females, even though the ratio of males to females is still roughly 4:1 [3]. These trends are also associated with fewer complete (AIS grade A) injuries [1].

Accompanying these demographic differences, there have been studies which explored the impact of age at injury and of the impact of duration of injury. Sustaining a traumatic SCI later in life (age >70 years) is associated with longer surgical wait times and poorer outcomes than younger patients, despite having less severe injuries [4]. A longer rehabilitation period and lower functional independence measure scores at discharge are deemed

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partially a result of greater comorbidities such as obesity [7]. As age of injury increases, there is a greater chance of having a higher education level, being married, being discharged to a nursing home, and having an incomplete versus complete injury [7]. The latter point is primarily related to a transition from vehicular and sports-related aetiologies to falls causing injuries with increased age [3]. Those in stable employment post-injury are, however, more likely to have been injured earlier in life [8]. Duration of injury often aligns to aging with an SCI and entails its own challenges. The effects of aging may appear sooner post-SCI and include psychosocial factors such as functional decline, changes in support structures, and economic instability [9].

To further current research, we approached it from a new angle by comparing the aging experience between those injured at different ages. This study identified a group of adults in a similar age bracket (>55 y) and compared those who had experienced an SCI early in life as opposed to late. The goal was to (1) compare psychosocial and quality of life outcomes between groups, and (2) explore their post-injury experiences. We anticipated that participants would experience different outcomes as a function of their age at the time of SCI.

METHODS

This study used a mixed-method design and received ethical approval from the local university Behavioural Research Ethics Board and the health authority.

Participants

We purposively recruited participants based on our inclusion criteria and our goal of recruiting 15 participants in each group. Beyond that, we did not dive deeper into individual factors when recruiting and assigning participants. To be included in the study, participants needed to be able to communicate in English, provide their own consent, be ≥ 55 years of age, and have sustained an SCI either early in life (before age of 30) or later in life (after age of 50). The latter group needed to have had an SCI at least two years prior. Participants were recruited via third party recruiters from a local SCI support organisation, from a list of previous research participants who indicated interest in future studies, and from advertisements posted in local rehabilitation and research centres.

Quantitative procedures

Participants completed self-report questionnaires in the location of their choice (e.g. home or research facility). They completed them independently or with the assistance of a trained research assistant. Outcome measures were chosen based on their psychometric properties in the SCI population and their adherence to the Disability Creation Process (DCP) explanatory model for the consequences of disease and injury [10]. This model suggests that the consequences of disease are based on the interplay of three factors: personal factors (i.e. level of ability, demographic factors), environmental factors (i.e. physical and social environments), and life habits (e.g. participation) [10]. The tools used to obtain the outcomes measures are described in Table 1.

Qualitative procedures

We used a qualitative description methodological approach as described by Sandelowski, with analysis and reporting of findings remaining close to the data [11]. All 30 participants were interviewed once, either in person or over the phone. Interviews were conducted by the first author or a trained research assistant using a semi-structured interview guide. The researchers' backgrounds were in occupational therapy, medicine, and anthropology, respectively. They had no prior relationship with the participants. Examples of questions from the interview guide included, 'What is life like for you today?' and 'What (physical, psychological, social) changes have you experienced since you were discharged?' Each interview lasted 30–60 min and was audio-recorded and transcribed verbatim.

Analysis

Data from the questionnaires were entered into Microsoft Office Excel 2007 and checked for accuracy. Statistical analyses were performed using

the Statistical Package for the Social Sciences (SPSS). In general, when a scale used a total score based on summation, missing data was given a value of zero, and when values were multiplied, missing responses were handled as the lowest possible value for that item. Missing annual income data were estimated by assigning participants the mean annual income for their postal code [12]. Descriptive statistics were calculated to describe the sample. To explore the comparability of both groups, an independent samples *t* test was performed for continuous variables and the Chi-square test was conducted for the categorical variables. The 2×2 table values were used if any assumptions of the Chi-square test were violated. Statistical significance was defined as a $p \leq 0.05$.

Thematic content analysis was performed on the interview transcripts using NVivo software according to analysis process outlined by Anderson [13]. This included finding units of meaning, compiling units of meaning into codes, developing codes across transcripts, and constructing themes from the codes. We employed trustworthiness strategies including triangulation and reflexivity. For triangulation of researchers, authors WBM and ES initially coded transcripts independently before coming to consensus about codes and themes which were agreed upon by the entire authorship team. To facilitate reflexivity, interviewers identified the responses they expected from participants to the interview guide and probed for alternative examples to avoid confirmation bias.

RESULTS

Quantitative results

Table 2 reports the demographic characteristics and outcome measure results of the early and later SCI groups. Annual income was imputed for four participants in the later SCI group based on the mean income of people living in their postal code. The early SCI group had a larger proportion of complete injuries (40%) than the later SCI group (13%). The later SCI group had a greater proportion of married/common-law participants than the early SCI group. Three statistically significant differences were identified between groups: there were more females in the later SCI group, annual income was lower in the early SCI group, and a larger proportion of later SCI group lived-in long-term care.

Qualitative results

We identified three main themes: 'dealing with health and changes in function', 'enacting interdependence', and 'living in the community'. Each theme was composed of multiple sub-themes, exemplifying similarities and differences between the early and later SCI groups.

Dealing with health and changes in function. The first theme describes how participants interacted with the health care system following their injury and how they coped with the difficulties of living with an SCI. For example, a participant from the early SCI group stated:

"With my shoulder the way it was, it was hard to transfer anywhere, to my bed, washroom, tub, those were three areas that were the toughest with my one arm. [...] It exhausts you [...] when you're trying all these things because... sometimes my arms would give away and I'd end up being on the floor so that would take me sometimes 3 h to get back to where I started from [...]. So, it was very frustrating, but you know you work through it and you learn [...] how to transfer yourself in different ways." (P2)

In the sub-theme, *dealing with age-related changes*, participants in the early SCI group identified changes more often. These changes were often related to stamina and a decreased ability to complete everyday tasks as illustrated by a participant from the early SCI group:

"I used to be able to transfer [in and out of a car 3–4] times a day, [...] it wasn't a big deal- you didn't really think twice about it. And as you get older, particularly after 50, your strength just

Table 1. Description of quantitative outcome measures.

Factor	Tool	Description
Personal Factors	Demographic information	Included age, age at injury, sex, type of injury, ambulatory status, secondary diagnoses, and annual income.
	Spinal Cord Independence Measure (SCIM)	The SCIM was used to assess function in the domains of self-care, mobility, respiration, and sphincter management [25]. The tool has 19 items and provides a total score (0–100). The SCIM has excellent inter-rater reliability with an intraclass correlation (ICC) for the total score of 0.956.
	Hospital Anxiety and Depression Scale (HADS)	The HADS is a 14-item, self-reported assessment of anxiety and depression that has been validated for use in SCI patients [26]. The tool provides sub-scale scores for anxiety (0–21) and depression (0–21) and has been shown to correlate well with other measures of the same constructs (r ranging from 0.49–0.83). The HADS has two-week test-retest reliability of 0.84 for anxiety and 0.85 for depression.
	Late Life Function and Disability Instrument (LLFDI)	The LLFDI is a self-report tool that asks participants about the frequency and perceived limitations when performing common social tasks such as household chores or inviting other people for social events [27]. The 16-item tool outputs a frequency score (16–80) and a limitation score (16–80). The LLFDI score was positively associated with the severity of functional limitation and scores were found to differ in significant ways based on functional limitations. The 3-week, test-retest reliability across domains ranged from $r = 0.68$ –0.82.
Environmental Factors	Demographic information	Included information regarding living environment.
	Craig Hospital Inventory of Environmental Factors (CHIEF)	The CHIEF is a self-report assessment of environmental barriers to social participation for people with disabilities [28]. This measure is a 25-item tool which provides a total score of 0–200. The CHIEF has demonstrated a 2-week test-retest reliability of $r = 0.93$ in patients with SCI.
Life Habits	Life Space Assessment (LSA)	The LSA examines respondent mobility, frequency, and independence measured in 5 increasingly larger life spaces (i.e. home, yard, neighbourhood, town, outside town) and generates a total score out of 120 [29]. The LSA was found to be positively correlated with physical performance ($r = 0.603$) and self-reported health ($r = 0.421$) and was negatively correlated with depression ($r = -0.411$). The LSA had a 2-week test-retest reliability of 0.87.
Quality of Life	World Health Organisation Quality of Life – Brief version (WHOQoL-BREF)	Although the DCP model does not explicitly include quality of life, previous work has identified it as a holistic measure of social and environmental satisfaction and useful for SCI research. The WHOQoL-BREF is a 26 item self-report assessment of health-related quality of life [30]. It provides adjusted domain scores of physical health (4–20), psychological health (4–20), social relations (4–20), and environment (4–20) that can be averaged to provide a general measure score (4–20). Among people with SCI, WHOQoL-BREF scores have been found to be moderately correlated with Satisfaction with Well-Being index scores.

starts to go and you start noticing that things are getting hard and harder and then really hard and then you, just can't." (P26)

Fewer participants in the later SCI group described these kinds of changes. They indicate, however, how their SCI contributed to a sense of faster aging, with pains and struggles from aging accumulating with pains related to their SCI. A participant from the later SCI group stated:

"I feel like I've been hit by a double whammy of you know, the regular aches and pains and stiffness that you get from aging if you don't move combined with all the ones I already have, and it's really bugging me, I feel like I'm aging faster." (P23)

In sub-theme, *what I would have done differently*, participants from the early SCI group reflected on mistakes and have more regrets than participants from the later SCI group, as illustrated by a participant from the early SCI group:

"Um...think in hindsight, I should have been more cognisant that I would have greater financial needs." (P10)

These regrets included not continuing their education, not making more use of the resources provided to them, not being more proactive concerning the help offered to them, and not dealing with their finances better. Participants in the later SCI group expressed these regrets less frequently.

Enacting interdependence. The second theme captures the process of seeking support from others while working towards a sense of pre-injury independence. Participants described several social and financial supports that helped them meet their needs (e.g., charity, family, friends, community-based initiatives). A participant from the early SCI group explains how they try to find a balance between independence and asking for support:

"If I have something physical to do, I would ask for help, but I'll try to stay as independent as possible. Even if I know it's gonna hurt, like, sometimes I do maintenance on my motorcycle, and, [for] that, I'll [be in pain for] two or three days for that." (P2)

Table 2. Participant demographic characteristics and outcome measures ($N = 30$).

Measure (Range)	Early SCI Group ($n = 15$), Mean \pm SD or n (%)	Later SCI Group ($n = 15$), Mean \pm SD or n (%)	P
Participant Background Characteristics			
Age	60 \pm 2	63 \pm 2	0.290
Age at injury	23.8 \pm 3.2	56.6 \pm 1.5	
Sex, female	2 (13)	8 (53)	0.020*
Complete injury	6 (40)	2 (13)	0.215
Functional injury type			0.715
Paraplegia	7 (47)	8 (53)	
Tetraplegia	8 (53)	7 (47)	
Ambulatory	5 (33)	3 (20)	0.472
Secondary diagnoses	9 (60)	9 (60)	1.000
Annual income (\$)			0.015*
<14,999	4 (27)	2 (13)	
15,000–29,999	4 (27)	2 (13)	
30,000–44,999	3 (20)	1 (7)	
45,000–59,999	4 (27)	3 (20)	
60,000–74,999	0	0	
>75000	0	7 (47)	
Living in a facility	0 (0)	5 (33)	0.014*
Married/ common law	3 (20)	7 (47)	0.121
Participant Outcome Measures			
SCIM (0–100)	55.9 \pm 6.1	43.0 \pm 6.0	0.144
HADS: Anxiety (0–21)	6.7 \pm 1.0	4.4 \pm 1.2	0.149
HADS: Depression (0–21)	6.2 \pm 1.0	5.3 \pm 0.9	0.492
LLDI: Frequency (16–80)	49.1 \pm 4.1	50.0 \pm 1.7	0.846
LLDI: Limitation (16–80)	49.5 \pm 5.1	52.3 \pm 2.8	0.632
CHIEF: Total (0–200)	22.2 \pm 3.7	22.3 \pm 5.1	0.992
LSA: (0–120)	53.2 \pm 6.1	50.9 \pm 4.7	0.767
WHOQoL-BREF: Average (4–20)	13.5 \pm 0.6	14.0 \pm 0.5	0.530

SCIM spinal cord injury measure, HADS Hospital anxiety and depression score, LLDI late life disability index, CHIEF Craig Hospital inventory of environment and inventory factors, LSA life space assessment, WHO-QoL BREF World Health Organisation quality of life – brief version.

* $p < 0.05$.

The codes generated in support of this theme were similar across participants from both groups. For example, a participant from the later SCI group also stated a desire to do certain things themselves:

“Well, when I go to bed at night, I like to take off my own sweater and shirt and stuff.” (P29)

For both groups, a reduced sense of independence signified a substantial loss and required finding a new harmony of interdependence.

Living in the community. The third theme encompasses changes to participant activities and social participation, and issues with

ableism. Whereas some participants experienced a loss in their participation, others found new activities to participate in post-injury. A participant from the later SCI group stated:

“I used to do a lot of sports. I still watch it, but I can’t do any right now. I have to do light sports, not [the more intense sports I used to do]. [...] For a long time [after my injury], I didn’t even want to look at sports. It took me a while to say, alright I am going to watch this again.” (P8)

In the sub-theme, *ableism and ageism*, participants from the early SCI group suggested more resilience and conformity, when talking about ageism, compared to participants from the later SCI group. Participants from both groups, later SCI in particular, indicated that people treated them differently and with more indifference. They note personal vexations of able-bodied individuals misappropriating services, such as parking spots, for people with disabilities, with a participant from the early SCI group stating:

“I get so mad when I see someone sitting in their car. I don’t mind if they’re using it to park, but when you’re just, you know, idling there while some able-bodied person runs in and does their errands, and they just sit there taking up the spot. It says right on the plaque that you’re not supposed to do that.” (P11)

For the sub-theme, *becoming more compassionate*, several participants in the later SCI group expressed how they became more compassionate or empathetic with greater understanding and awareness. A participant from the later SCI group stated:

“Now I understand a lot more about people, and I’m more able to see the person and not the wheelchair, or disability, and I understand that when people maybe, look all pinned up in a chair, [...], they’re not retarded.” (P15)

In the sub-theme, *changes in employment and education*, those who were injured earlier in life were still in school or not already working, so they encountered issues finding work.

Participants from the later SCI group reported difficulty being able to return to their previous jobs. One participant stated:

“Mentally it was hard to focus, physically, it’s physically very uncomfortable and difficult. But the other thing that I find since my accident is that I’m really tired all the time. [...]. I find the stamina for work is tough. [...] An eight-hour day is hard, [...], what I’ve had to do is I’ve had to cut my work down to five months a year. I’ll do a project then I can’t do one for a while. By the end of it it’s so difficult for me.” (P23)

Some did have positive experiences with returning to work, but this was not the case for all, as illustrated by the physical struggles of P23 above.

DISCUSSION

Little research has explored the experiences of people within the same age bracket who sustained SCI at different ages. Our findings are consistent with the DCP model. Quantitative analysis found statistically significant differences regarding personal and environmental factors, including sex, annual income, and location of residence. As mirrored in previous research, the higher percentage of males in the early SCI group is likely due to cause of injury, with vehicular accidents being the leading cause in the early SCI group and falls becoming an increasingly common cause in the later SCI group [1, 3]. The higher annual income reported by the later SCI group is likely because, although those injured early in life were more likely to find or return to work, their level of

experience or education may not allow them to reach positions of higher incomes. Only two-thirds of the later SCI group reported living at home compared to all the early SCI group and might be related to research demonstrating they have poorer outcomes post SCI, despite generally having less severe injuries [14]. Additionally, the role of ageism may be influential as those of an older age reportedly receive significant differences in access to treatment [15]. This possible link between ageism and rehabilitation potential is congruent with anecdotal evidence that rehabilitation facilities preferentially admit younger patients. Although, the poorer health outcomes may be inevitable, it would seem there is an element of ageism that needs addressing in current rehabilitation practices.

The limited number of quantitative differences could indicate an issue with representativeness, considering it was a small sample. However, participants displayed similar demographics (e.g. complete vs incomplete; para vs tetraplegia) to larger population-based studies, such as the 2015 Annual Report in the USA [2]. Nevertheless, larger samples may yield different findings, and this could be explored in future studies.

Analysis of the qualitative data revealed more areas of divergence especially regarding life habits, which was consistent with our initial expectations. Having experienced aging with their SCI, the early SCI group reported more age-related changes and issues compared to the later SCI group with relatively recent injuries. More time spent with disability may explain why the early SCI group seemed to reflect on mistakes and have more regrets than participants from the later SCI group. Groah et al. reported that people with an SCI face additional challenges in their aging trajectory, including the limitations described by our participants along with greater risk of obesity, pressure sores, and reduced bone mineral density [16]. Current rehabilitation practices include educational sessions relating to self-management outside of the hospital but a scoping review by McIntyre et al. found that the programs often focus on pain with a potential lack of focus in areas of life such as exercise, nutrition, and community reintegration [17]. Rehabilitation programs may need to increase awareness among patients of the lifestyle factors that may dispose them to secondary conditions.

In the second theme, limited variation was present with both groups displaying a desire for independence. Western cultures generally emphasise the importance of individual independence, historically identifying independence and dependence as dichotomous concepts [18]. Consequentially, Western societies preferentially enable those deemed independent. A lack of funding and services for individuals with disabilities creates an imperative for independence for anyone who desires to age-in-place (e.g. staying at home and avoiding residential care placement) [19]. Culturally, individuals of a higher social class, greater wealth, have the potential for greater 'independence' because they can afford the equipment and services needed to live in the community [20]. Despite the higher incomes, however, participants in the later SCI group were more likely to live in a facility. Based on our findings, it appears that higher income may not be a protective factor for avoiding placement into a care facility. Our study was conducted in Canada, however, which has a universal health care system. It is, therefore, possible that higher income could be more influential as a protective factor in countries without universal health care.

The third theme illustrates the challenges of living in the community. Along with employment challenges in both groups, this theme raised concerns with enacted stigma, which refers to experiences of discrimination and unfair treatment by others [21]. Concerning initial attempts for those with SCI to re-enter and remain in the workforce, Reed et al. highlighted four key themes, 'adjustment and dealing with emotional reactions', 'gaining self-confidence', 'preventing burnout' and 'attitudes and perspectives' [22]. Return to a previous employer can simplify the process for those who were already in the workforce, assuming the

employment identity corresponds to a proposed role [23]. Return to work is frequently a lengthy process and barriers increase with age. The implementation of structured psychological interventions during rehabilitation, that extend across both the acute and chronic phases, may foster a greater adjustment to the psychosocial changes experienced when re-entering the community. Interventions to facilitate emotional and behavioural change using cognitive behavioural therapy have demonstrated promising results among individuals with SCI [24].

Limitations of the study primarily relate to sampling. A relatively small sample was recruited using purposive sampling methods. This may have resulted in selection bias by missing isolated or immobile patients who comprise a large proportion of the SCI population. Some significant differences may have arisen from multiple testing and there is also the potential for social desirability biases with self-report measures.

Despite limitations, our study was successful in highlighting avenues where additional support or interventions could be implemented. Post-SCI care services need to consider age of injury to maximise rehabilitation potential for all individuals with SCI and reduce the risk of poorer outcomes being experienced by those injured later in life. Strategies should be explored to help those injured early in life achieve higher annual incomes and to help those injured later in life have the opportunity to age in place. Across all age cohorts, it is important to address the desire for greater independence, provide greater support in returning to the workforce, and encourage a societal shift to reduce enacted stigma.

CONCLUSION

Our results suggest that age of injury has associations with each component of the DCP. Similarities and differences can be seen for personal factors, environmental factors, and life habits between those injured early in life compared to later in life. The key differences relate to sex, annual income, location of residence, and experience of aging along with other psychosocial outcomes. Further research could explore the emerging trends and themes in the aging SCI populations with larger samples.

DATA AVAILABILITY

Available data are presented within the article.

REFERENCES

- Chen Y, He Y, DeVivo M. Changing demographics and injury profile of new traumatic spinal cord injuries in the United States, 1972–2014. *Arch Phys Med Rehabil.* 2016;97:1610–9.
- National Spinal Cord Injury Statistical Center (NSCISC). Complete public version of the 2015 annual statistical report for the spinal cord injury model systems. Birmingham: NSCISC; 2015.
- Jackson A, Dijkers M, DeVivo M, Poczatek R. A demographic profile of new traumatic spinal cord injuries: change and stability over 30 years. *Arch Phys Med Rehabil.* 2004;85:1740–8.
- Ahn H, Bailey C, Rivers C, Noonan V, Tsai E, Fourney D, et al. Effect of older age on treatment decisions and outcomes among patients with traumatic spinal cord injury. *Can Med Assoc J.* 2015;187:873–80.
- Adriaansen J, Ruijs L, van Koppenhagen C, van Asbeck F, Snoek G, van Kuppevelt D, et al. Secondary health conditions and quality of life in persons living with spinal cord injury for at least ten years. *J Rehabil Med.* 2016;48:853–60.
- Noonan V, Fingas M, Farry A, Baxter D, Singh A, Fehlings M, et al. Incidence and prevalence of spinal cord injury in Canada: a national perspective. *Neuroepidemiology.* 2012;38:219–26.
- Hsieh C, DeJong G, Groah S, Ballard P, Horn S, Tian W, et al. Comparing rehabilitation services and outcomes between older and younger people with spinal cord injury. *Arch Phys Med Rehabil.* 2013;94:175–86.
- Hilton G, Unsworth C, Stuckey R, Murphy G. The experience of seeking, gaining and maintaining employment after traumatic spinal cord injury and the vocational pathways involved. *Work.* 2018;59:67–84.

9. Charlifue S, Jha A, Lammertse D. Aging with spinal cord injury. *Phys Med Rehabil Clin N. Am.* 2010;21:383–402.
10. Fougeyrollas P, Boucher N, Edwards G, Grenier Y, Noreau L. The disability creation process model: a comprehensive explanation of disabling situations as a guide to developing policy and service programs. *Scand J Disabil Res.* 2019;21:25–37.
11. Sandelowski M. What's in a name? Qualitative description revisited. *Res Nurs Health.* 2009;33:77–84.
12. Average income explorer [Internet]. Canada Census; 2016 [cited 2019]. Available from: <https://censumapper.ca/maps/1535?index=3#13/49.2782/-123.1338>
13. Anderson R. Thematic Content Analysis (TCA): descriptive presentation of qualitative data. 2007. (Unpublished manuscript).
14. Lidal I, Huynh T, Biering-Sorensen F. Return to work following spinal cord injury: a review. *Disabil Rehabil.* 2009;29:1341–75.
15. Buttigieg S, Illinca S, de Sao Jose J, Larsson A. Researching ageism in health-care and long term care. In: Ayalon L, Tesch-Römer C, editors. *Contemporary Perspectives on Ageism.* Springer, Cham; 2018. p. 493–515.
16. Groah S, Charlifue S, Tate D, Jensen M, Molton I, Forchheimer M, et al. Spinal cord injury and aging: challenges and recommendations for future research. *Am J Phys Med Rehabil.* 2012;91:80–93.
17. McIntyre A, Marrocco S, McRae S, Sleeth L, Hitzig S, Jaglal S, et al. A scoping review of self-management interventions following spinal cord injury. *Top Spinal Cord Inj Rehabil.* 2020;26:36–63.
18. Gross Z. How can we overcome the dichotomy that Western culture has created between the concepts of independence and dependence? *Educ Philos Theory.* 2015;47:1160–5.
19. Mortenson W, Sixsmith A, Beringer R. No place like home? Surveillance and what home means in old age. *Can J Aging.* 2016;35:103–14.
20. Hamamura T, Xu Q, Du Y. Culture, social class, and independence-interdependence: the case of Chinese adolescents. *Int J Psychol.* 2013;48:344–51.
21. Gray A. Stigma in psychiatry. *J R Soc Med.* 2002;95:72–6.
22. Reed K, Meade M, Krausse J. Impacts of health behaviours and health management on employment after SCI: psychological health and health management. *Top Spinal Cord Inj Rehabil.* 2016;22:111–20.
23. Hay-Smith E, Dickson B, Nunnerley J, Sinnott K. "The final piece of the puzzle to fit in": an interpretive phenomenological analysis of the return to employment in New Zealand after spinal cord injury. *Disabil Rehabil.* 2012;35:1436–46.
24. Post M, van Leeuwen C. Psychosocial issues in spinal cord injury: a review. *Spinal Cord.* 2012;50:382–9.
25. Itzkovich M, Tamir A, Philo O, Steinberg F, Ronen J, Spasser R, et al. Reliability of the Catz-Itzkovich Spinal Cord Independence Measure assessment by interview and comparison with observation. *Am J Phys Med Rehabil.* 2003;82:267–72.
26. Woolrich R, Kennedy P, Tasiemski T. A preliminary psychometric evaluation of the Hospital Anxiety and Depression Scale (HADS) in 963 people living with a spinal cord injury. *Psychol Health Med.* 2006;11:80–90.
27. Jette A, Haley S, Coster W, Kooyoomjian J, Levenson S, Heeren T, et al. Late life function and disability instrument: I. development and evaluation of the disability component. *J Gerontol.* 2002;57:209–16.
28. Whiteneck G, Harrison-Felix C, Mellick D, Brooks C, Charlifue S, Gerhart K, et al. Quantifying environmental factors: a measure of physical, attitudinal, service, productivity, and policy barriers. *Arch Phys Med Rehabil.* 2004;85:1324–35.
29. Baker P, Bodner E, Allman R. Measuring life-space mobility in community-dwelling older adults. *J Am Geriatr Soc.* 2003;51:1610–4.
30. The WHOQOL Group. Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychol Med.* 1998;28:551–8.

AUTHOR CONTRIBUTIONS

ES: analysis, writing. BS: conceptualisation, methodology, writing. SF: conceptualisation, methodology, writing. CLB: conceptualisation, methodology, writing. DS: conceptualisation, methodology, writing. MV: investigation, analysis, writing. WBM: conceptualisation, methodology, analysis, investigation, writing, supervision.

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