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**Why do challenges still exist in primary care for patients with spinal cord injury?
Exploring the medical model through a social disability lens**

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Abstract

Despite having high healthcare needs, individuals with spinal cord injury (SCI) receive suboptimal primary care; they are less likely than able-bodied persons to receive preventive care and more likely to have unmet health care needs. The aim of this mixed quantitative (surveys) and qualitative (interviews) study was to gather primary care health provider and rehabilitation specialists' perspectives on why these challenges persist despite the increasing body of evidence identifying delivery service gaps. Surveys were completed by 12 family physicians who referred individuals with SCI to an interprofessional primary care mobility clinic. Interviews were completed with eight SCI rehabilitation providers. Questions in both the survey and interviews were asked related to the barriers to the provision of optimal care for SCI, potential solutions, and preferred methods for knowledge dissemination. Skill and attitudinal reasons were offered for the lack of evidence to practice transfer including: the absence of patient self-management, poor access to specialists, lack of education for family practice physicians, fragmentation of community resources and co-ordination upon hospital discharge. Solutions offered included greater patient self-management, better access to specialists, specialized primary care services and provision of SCI guidelines and protocols. Participant explanations and solutions were then analyzed through a social disability lens to see if new understandings could be identified to explain the lack of uptake from research findings to clinical practice for this underserved vulnerable population.

Keywords

Spinal cord injury, primary care, knowledge translation, quality improvement, mixed methods

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Background

Individuals with SCI face several challenges in maintaining health and wellness. Inaccessible medical practices are common and pose environmental barriers to health care access (McMillan et al. 2016). Physically inaccessible medical offices, examination rooms, equipment and washrooms are known barriers to care for individuals with SCI (Veltman, Stewart, Tardif, & Branigan, 2001). Other barriers include negative attitudes toward disability, limited professional knowledge of the needs of individuals with SCI and health system disincentives for providing care to this population (McMillan, Lee, Milligan, Hillier, & Bauman, 2016; Morrison, George, & Mosqueda, 2008). These barriers contribute to preventable emergency department visits for issues that could be managed in primary care (Guilcher, Craven, Calzavara, McColl, & Jaglal, 2012). Despite primary care being the best setting to provide positive outcomes for those with spinal cord injuries, family physicians perceive themselves as unprepared to manage SCI care and low patient volumes contribute to decreased incentive to build clinical capacity for optimal SCI care (McMillan et al., 2016). Although the majority of patients may have a family physician, fewer have SCI specialists, leaving them with minimal expertise to manage their care (Donnelly et al., 2007). Individuals with SCI who have a specialist will often access their specialist for basic health issues that could be best managed in primary care (Johnston, Diab, Chu, & Kirshblum, 2005).

There is evidence in the literature that primary care for individuals with physical and sensory disabilities is less than adequate and they are less likely to receive the same level of preventive care and more likely to report unmet health needs than able-bodied persons (Stillman, Frost, Smalley, Bertocci, & Williams, 2014). A scoping review found evidence of challenges related to access to care and unmet needs among this patient population (McColl, Aiken, McColl, Sakakibara, & Smith, 2012). Several studies reported that individuals with SCI lack optimal primary care in a number of areas including skin care, pain, and sexuality (van Loo, Post, Bloemen, & van Asbeck, 2010; Stillman et al., 2014). Similarly, individuals with SCI are less likely to receive cancer screening (colorectal, breast, and cervical) than the general population (Stillman et al., 2014). A study of 108 patients with SCI found that the majority (89%) had not been weighed during their last visit with their family physician and were not examined on an examination table (Stillman et al., 2014).

While there is lived experience literature available on the perspectives of individuals with SCI, less research has been conducted on the perspectives of those considered to be experts working with this population such as family physicians and rehabilitation specialists. Little is known why practice knowledge from these two groups diffuses slowly into clinical practice changes (Kristensen, Nymann, & Konradsen, 2016). It is known that research outcomes can take up to a decade to transfer into clinical practice. Sustainability of change can also be a challenge (Ploeg et al., 2014).

This study therefore aimed to gather the perspectives of physician and SCI rehabilitation providers on the barriers to optimal primary care and what might act as strategies for improvement to close the practice gap that continues to persist for this vulnerable service user group. As such, we used the social model of disability which situates barriers and remedies outside of the person as compared to the medical model which situates barriers and impediments within the person.

Our study was also informed by the theoretical framework of Klein and Knight (Klein & Knight, 2005) to facilitate a greater understanding of why primary care for persons with SCI was not in keeping with current best practices. Klein and Knight identify five organizational factors that act as barriers to clinical implementation:

1. quality and quantity of training, organization receptiveness for research to clinical implementation, including beliefs in the importance of change;
2. management support for change;
3. availability of enough financial resources to support change;
4. a receptive learning culture that supports and enables knowledge and skill development; and
5. leadership to guide such change.

Methods

Design

We used a mixed method design and purposive sampling to collect data from two key informant groups: individuals working in SCI-related rehabilitation and family physicians who provide primary care to patients with SCI, in Ontario, Canada. We selected these two groups of providers to understand from their perspectives the barriers that prevent research evidence to be translated into clinical practice. We were also interested in knowing what would act as

facilitators in supporting evidence-based findings into practice solutions. Mixed methods were used to enhance the validity of the study findings through convergence and integration of results and to enhance our understanding of the findings from the questionnaires and interviews (Creswell & Piano, 2007). Using this exploratory sequential design, questionnaire data were collected first, followed by interview data, consistent with a mixed method protocol (Creswell & Piano, 2007). Barriers impeding the research to clinical practice transfer identified by Klein and Knight (2005) informed our codebook for the interviews and questionnaire.

Participants

Family physicians who referred patients with SCI to the [Blinded Site] Family Health Team Mobility Clinic within a one year time period were invited to participate in this study. The [Blinded Site] Mobility clinic, located in [Blinded Location], provides a comprehensive assessment, incorporating patient goals within a shared care approach (Lee, Milligan, Hillier, & McMillan, 2014; Lee, Milligan, Hillier, & McMillan, 2013). In addition, individuals known to the authors to have experience with SCI rehabilitation and community services were invited to participate in individual telephone interviews.

A total of 12 questionnaires were completed by family physicians (36% response rate; N=12/33) and eight key informant interviews were conducted with individuals with SCI-related rehabilitation and community service experience (53% response rate; N=8/15). Characteristics of these respondent groups are presented in Table 1. Five of the eight key informants had practice/work activities that focused solely or primarily on SCI; the remaining three had extensive experience working with individuals with SCI.

Table 1
Questionnaire and interview respondent characteristics

Characteristics	% (N)
Family Physician Questionnaire Respondents (N = 12)	
Age, years	
25-30	8.3 (1)
31-40	33.3 (4)
41-50	33.3 (4)
51-60	16.7 (2)
61-70	8.3 (1)

Characteristics	% (N)
Gender	
Female	41.7 (5)
Male	58.3 (7)
Time in practice, years	41.7 (5)
≤9	
10-19	33.3 (4)
20-29	16.7 (2)
>30	8.3 (1)
Total number of patients in practice	8.3 (1)
≤500	
501-1000	16.7 (2)
1001 – 1500	50.0 (6)
1501-2000	25.0 (1)
≥2001	0
Total number of patients with SCI	
None	8.3 (1)
1-2	50.0 (6)
3-4	25.0 (3)
5-10	16.7 (2)
Interview Participants (N = 8)	
Discipline – Rehabilitation Program	
Clinical Nurse Specialist/ Educator	12.5 (1)
Physical Therapist	25.0 (2)
Recreation Therapist	12.5 (1)
Discipline - Community Services	25.0 (2)
Kinesiologist	
Physiotherapist	12.5 (1)
SCI specific service coordinator/ advocate	12.5 (1)

Note: Percentages may not sum to 100% due to missing values.

SCI = Spinal Cord Injury

Measures and Data Collection

(i) Family Physician Questionnaire

A questionnaire for family physicians was developed specifically for this study. Within the questionnaire, respondents were provided a list of known existing barriers to SCI primary care identified in the literature (McMillan et al., 2016; Stillman et al., 2014; McColl et al., 2012)

and were asked to rate the extent to which each of these barriers impacted their ability to care for individuals with SCI (4-point scale: 1=not at all; 4=a major barrier). These barriers are listed in Table 2. Similarly, participants were asked to rate the helpfulness (5-point scale: 1=not at all; 5=extremely helpful) of strategies identified in previous research as opportunities to support family physicians to provide better care (McMillan et al., 2016). Participants were asked whether they needed more professional development related to SCI (yes, no, not sure); those providing 'yes' or 'not sure' responses were provided with a list of potential opportunities for continuing education and were asked to select those that were most beneficial. Demographic information (age, gender, years in clinical practice, number of patients in their practice and number of patients with SCI in their practice) was also collected.

Family physicians were invited to participate in this study via email web-link to the online questionnaire (posted on Survey Monkey: www.surveymonkey.com) was included with the study invitation. Invitations to complete the surveys were distributed between November and December 2015.

(ii) In-Depth Interviews with SCI Rehabilitation Key Informants

Interview participants were provided with a summary of the results of the family physician questionnaire and the interview questions prior to the interview. During the interview they were asked to reflect on the questionnaire results related to barriers to the provision of primary care for persons with SCI and opportunities for improvements. They were asked to comment on whether the results reflected their own practice experiences and whether they had anything to add to our understanding of these areas. Interview participants were also asked to identify their discipline/role and the extent to which their practice involves caring for persons with SCI.

Interview participants were invited to participate in this study via e-mail. All interviews were conducted between July and October 2016 by one author to ensure consistency and to remain as close to the data as possible (Creswell, 2007). Interviews were audio recorded and transcribed.

Data Analysis

Questionnaire data were analyzed using SPSS (IBM SPSS Version 24.0, Armonk, NY) to generate frequencies, weighted means and standard deviations. Transcripts were analyzed using a naturalist inquiry approach to provide a deeper understanding of participant perspectives on SCI primary care (Lincoln & Guba, 1985). Responses were compared, contrasted and categorized to create a summary of responses that were then used to identify reoccurring themes in the data (Lincoln & Guba, 1985) and to validate and integrate with survey findings (Creswell & Piano, 2007). This inductive analysis was conducted separately by two of the authors [Blinded Author Initials] who reviewed the transcripts to identify themes in the data and to confirm saturation and reliability. Trustworthiness of the key themes generated by the analysis was verified with illustrative quotes from the interview transcripts.

This study was approved by the [Blinded Location] Integrated Research Ethics Board, [Blinded] University.

Results

Barriers to optimal SCI care

Table 2 presents the barriers physicians identified that impacted their ability to care for persons with SCI. Mean ratings reflected that almost all of the listed barriers to the provision of care for individuals with SCI were perceived as being ‘somewhat’ or a ‘major’ barrier. Major barriers were the lack of specialized equipment in the office (3.6/4) and limited medical training or clinical experience with secondary complications associated with SCI (3.5/4). The mean rating for lack of space or accessible office (2.4/4) reflected that this was perceived as a ‘slight’ barrier. The mean ratings for all other barriers reflected that they were perceived as ‘somewhat’ of a barrier (range = 2.7 – 3.4/4) Four key themes were generated from the analysis of interview data related to barriers to care. 1. Lack of knowledge of available community services and resources among health care professionals, service providers, and consumers; this lack of knowledge was attributed to SCI being a low prevalence condition. 2. Lack of time within the current structure of primary and community care to manage SCI health issues; time allotted for medical appointments and home-based personal care is limited and unrealistic; 3. Lack of integration and continuity of care across health sectors; patients often move between sectors (rehabilitation,

community, acute care, primary care) without any one sector being primarily responsible for their overall care. 4. Limited availability of accessible and affordable transportation services; this poses a significant barrier to the use of community services and programs and access to primary care.

Opportunities to improve SCI Care

Mean ratings of the potential helpfulness of various strategies to overcome existing barriers to SCI care reflected that survey participants perceived access to a specialized SCI clinic within primary care as ‘extremely’ helpful (4.7/5; Table 3). Mean ratings were lower for access to e-consultation with a specialist (4.4/5), greater access to practice guidelines specific to this population (4.2/5), and greater patient self-monitoring, but nonetheless these reflected the perception that these strategies would be ‘very’ helpful for overcoming barriers to SCI care. Table 4 presents physicians’ preferred method of knowledge dissemination. Nine survey respondents (75%) indicated that they required further professional development related to SCI care; three were unsure. The most frequently endorsed methods of knowledge dissemination included didactic opportunities (lectures delivered locally, lectures delivered within their practice setting, 92% and 58%, respectively) and small group learning delivered by a specialist (75%) and clinical support tools and job aides (50%).

Generally, interview participants concurred with the quality improvement strategies identified by family physicians and identified additional strategies from their rehabilitation program perspective. Five themes were generated from the analysis of interview data related to opportunities for improving primary care for individuals with SCI: 1. Use of multidisciplinary team approaches to care; 2. Better awareness of available community supports and services; 3. Better supports for community integration; 4. Greater family physician access to consultation supports; and, 5. More patient education to support self-management.

Table 2

Weighted means of physician ratings of the barriers that impact their ability to care for persons with spinal cord injury (N= 12)*

Barriers	Weighted means (SD)
Lack of specialized equipment in the office (height adjustable table, transfer lift, wheelchair scale)	3.6 (.73)
Limited medical training or clinical experience with secondary complications associated with SCI.	3.5 (.61)
Low volume of patients with SCI in practice	3.4 (.50)
Limited knowledge of the management of SCI-related issues.	3.4 (.60)
Limited knowledge of the assessment of SCI-related issues.	3.3 (.57)
Limited availability of specialists to consult with for advice on caring for patients with SCI.	3.3 (.93)
Limited knowledge of SCI-related community services/ resources.	3.2 (.78)
Lack of easily accessible best practice guidelines for SCI complications.	3.1 (.66)
Limited access to interprofessional care (social workers, occupational and physical therapists).	3.0 (1.1)
Lack of readily accessible physician-friendly screening, assessment tools, and resources	2.9 (.68)
Limited staff training to use specialized equipment.	2.9 (.72)
Lack of staff to assist with patient care in the office.	2.7 (.90)

Barriers	Weighted means (SD)
Lack of space, accessible office.	2.4 (1.1)

Note: Percentages may not sum to 100% due to missing values.

SCI = spinal cord injury

*4-point scale: 1 = not at all a barrier; 4 = major barrier

Results from Interviews with SCI-Rehabilitation Key Informants

Six themes were generated from the interviews with SCI rehabilitation key informants relating to the identification of gaps and possible recommendations toward the provision of optimal primary and community care. A description of each theme with supporting quotes is provided.

Theme 1 – Knowledge gaps regarding community services and supports

The issue of healthcare providers not knowing what services existed in the community functioned as a barrier when ensuring care was seamless as patients transitioned from inpatient to outpatient domains of care. The low volume of individuals with spinal cord injury seen was cited as the reason for not knowing what services existed as demonstrated by the quote, *“it’s likely related to the low volume of patients with SCI and I would say the same in terms of community services too”* [KSID1]. The provider added that services “out there,” meaning the community, were unknown, limiting support to patients who were transitioning back home. As a solution this provider proposed “something like a catalogue of what services are available and how you use them” [KSID1].

The lack of knowledge among professionals often resulted in patients navigating supports in the community themselves, either through their own research or by asking other SCI patients. One rehabilitation expert said, *“It’s still very much a ‘who knows who?’ kind of situation that people find themselves in”* [KSID6] meaning some patients were successful while others were not.

A different dimension related to the knowledge gap had less to do with the provision of expert care and more to do with the practicalities of returning home. Health care was often defined as services that took place in an institution as compared to the community or home. For example, although the logistics of transportation was cited as a challenge most SCI patients encountered, such items were not seen as part of institutional care. As [KSID8] said,

“It’s true, when they get home it’s like, ‘but I have nothing to do. I don’t know how to get anywhere. I don’t know where to go. I have no idea how to even get on a bus.’”

Lastly, the lack of relationship existing between professionals and services was identified as a gap for SCI patients. This lack of relationship contributed to the knowledge gap with one expert stating,

“I’m not really familiar what services are out there and although we’re doing a lot of work to try and improve our relationship with [home care services] we don’t know who to connect people with. It’s really up to the patient.” [KSID6].

Theme 2 - Lack of time within current primary care to provide optimal care

Time was identified as a valuable but scarce commodity within the existing infrastructure of healthcare services for SCI patients. The unique health conditions associated with a SCI did not conform to the time allotted to physicians for patient care as noted by this one participant,

“I mean generally when you go to see the family physician, you have 7 minutes and they’re [persons with SCI] not getting the care... because all of these things are inter-related, like you just can’t talk about the bowel without talking about the bladder without talking about the spasms. They’re sort of all related so I don’t think that it fits in with the model of the primary care one visit per issue. You can’t just go in with one complaint and get one prescription in your 7 minutes and leave,” [KSID6].

The logistics related to a standard physical examination was quoted as being a barrier due to the time involved as in, *“It’s time, it’s a huge factor. When you’re dealing with someone with spinal cord injury just the transfer from their chair to the examining table can take sometimes, 15 to 20 minutes so when you’re running a practice where you need to see lots of people, that can take up a lot of your time” [KSID2].*

Restrictive time allotments prescribed to community providers including personal service workers (PSW) resulted in shortcuts as noted by this one expert,

“Range of motion and stretching is important, but a lot of the people will say, ‘My PSWs....they don’t have time because by the time they help [the patient] with the bowel routine and bathing and getting dressed, that’s all the time they were allotted.’” [KSID7].

Theme 3 - Lack of integration and continuity of care across health domains

Fragmented services often left SCI patients lacking preventative care eventually resulting in serious health issues. Reasons given for the lack of integrated care included change in personnel, *“the case manager changes and so much gets lost,” [KS1D6]* to lack of communication between professionals,

“there’s not a formalized way for communication. They [the patient] may have a specialist or they may have an occupational therapist or social worker or other people working with them, but I find we kind of all do our own things, and it’s harder to have that sort of collaboration” [KSID3].

The severity of health issue resulting from this service fragmentation ranged from organ failure, described by one physician as occurring,

“often that’s what we see, they’re just go until their bowels are totally shot or they’re just having so much problems that they’re desperate for help [KSID5], to that of continuous rotation between hospitals described as “the patient moving from hospital to hospital. I’ve had people that go on the 5 hospital merry-go-round and it’s a nightmare” [KSID6].

When communication did occur, it tended to be episodic or transferred to the patient as seen by the statement,

“it’s disjointed, often when I’m seeing the client as a physiotherapist here in our clinic, we don’t often have a lot of communication with the physician. We do send them notes periodically but a lot of times we’re recommending to the patient oh you should go see your doctor about this and there’s not really a way for communication [KSID3].

A related dimension to fragmented services had to do with challenges experienced by family physicians accessing SCI specialists. As mentioned, the small number of SCI patients on family physician caseloads was attributed to a lower level of knowledge. It was expressed that, *“there is no access or mentor that they can call and collaborate with or get advice” [KS1D3],* accentuating the practice knowledge gap.

Theme 4 – Three A’s of Transportation - Availability, Accessibility and Affordability

Transportation was identified as a significant barrier in accessing health services in a timely, preventative and affordable way. While the logistics of arranging transportation was noted as in,

“getting to appointments, a specialist appointment, that’s a huge barrier or for some of our patients who live in some rural areas, there is nothing. No transportation exists” [KSID8],

there were also financial, physical and emotional costs noted as well. For example, it was the availability and costs associated with mobility services was emphasized as being prohibitive for some patients as very few individuals can afford a van or specially outfitted vehicle [KSID4].

Lack of mobility options can also meant that a SCI patient must travel long distances to receive care. The following quote highlights the physical and emotional costs that accompany this barrier;

“You could be coming to a half hour appointment or an hour appointment or even an outpatient clinic, you could be spending 4 hours a day in transit or more. So you’re picked up at your house, go to [location for transportation transfer across geographic boundaries], then wait for [transportation service] to come here, and then if they’re late, like you could be in transit for 4-5 hours, so by the time you get to the appointment you’re exhausted” [KSID1].

The link between transportation and social support was also noted as a critical component of healing and living with a SCI. The logistics of getting out can be overwhelming as highlighted by the quote,

“what often happens is they’ll sit at home and not go out if they don’t have anybody that’s going to help them. They may be terrified of going on the public transportation, like going on a bus, they don’t think they can do it” [KSID6].

Lack of accessible transportation was also linked to social isolation as highlighted by the statement, *“patients need access to transportation or are not going out or are more like sheltered and shut in and isolated”* [KSID8].

Theme 5 – Use of interdisciplinary team approaches

It was believed among the key informants that the best approach to SCI care was through an inter-disciplinary team to address the barriers of knowledge gaps and fragmented services due to the co-location of professions.

It was thought that the knowledge gap by physicians regarding community resources could be addressed by other members of an inter-disciplinary team including nursing, social work, occupational therapy and physiotherapy among others. One participant described the rationale this way,

“I don’t know that they’re [family physicians] going to have the knowledge [about

community services], *but they need to have somebody on their team that does have the knowledge. So I think the family medicine team is the way to go because I don't think it's the role of the doctor to know that. I think it's the role of the team to connect people, so they don't have to guess like they are now*" [KSID6].

Likewise, the barrier to booking and arranging transportation for multiple medical appointments at different locations was felt to be unnecessary if allied health professionals were co-located because,

"it's ideal and it's convenient for clients to access all of that in one location. Plus everyone has different knowledge and expertise in order to collaborate" [KSID3].

Theme 6 – Transfer to Self-Management Concept

The last theme related to transferring some self-care management over to patients, specifically a broader understanding of symptomatology specific to SCI diagnosis. Believing that self-education was a step toward feeling empowerment is seen in the quote,

"I think it's really important for them [persons with SCI] to understand how their new bodies work and the challenges that they experience about their new bodies and how to empower them with that knowledge" [KSID2].

It was stated that patients who could self-detect early symptoms of bladder infection would be *"extremely helpful if patients had the skills to effectively self-manage ...they could interact with their primary care physicians to be able to identify what they felt they would need"* [KSID6].

One participant also felt that coaching SCI patients on chronic pain management would be useful to manage this condition and a natural extension of the healthcare provider role, as in

"a lot of what I think the health care job is, it's not only to do that examination, but to educate the people with spinal cord injury on the signs and symptoms of a bladder infection or autonomic dysreflexia, so they know how to care for themselves and what to look for" [KSID1].

Table 3

Weighted means of family physicians' ratings of the potential helpfulness of various strategies to overcome barriers to the provision of the quality care for persons with spinal cord injury (N = 12)*

Potential strategies to overcome barriers	Weighted means (SD)
You could refer your patients with SCI to primary care-based accessible clinic for assessment and management of SCI-related issues	4.7 (.48)
You could access a specialist via secure e-mail for advice in a timely manner.	4.4 (.61)
You had greater access to SCI-related practice guidelines.	4.2 (.54)
Patients had skills or supports to effectively self-manage their care.	4.1 (.32)

SCI = spinal cord injury

*5-point scale: 1 = not at all helpful; 5 = extremely helpful

Table 4

Family physicians' preferred methods of knowledge dissemination (N = 12)

Method	% (N)
Continuing medical education lectures in your community/ region	91.7 (11)
Small group teaching by a specialist or expert family physician	75.0 (9)
Continuing medical education lectures in your practice	58.3 (7)
Point-of-practice tools/ job aides (web resource, pocket cards, specially designed chart forms, mobile apps)	50.0 (6)
One-day conference/ workshop	33.3 (4)
Handouts/ written materials	33.3 (4)
Clinical reasoning models/ algorithms	33.3 (4)
Mentorship/ observership opportunities	25.0 (3)
Continuing medical education lectures via videoconferencing	16.7 (2)

Self-instructional methods (videos, reading, web-based).	16.7 (2)
Other*	8.3 (1)

*Other: problem-based, interprofessional learning opportunities

Discussion

Why do barriers still exist for the SCI population – New insights

This study aimed to identify why barriers continue to exist for individuals living with spinal cord injury despite previous studies and current literature identifying barriers preventing the research to clinical practice. Themes garnered from the data included gaps of knowledge, both of best practices by physicians and that of available community programs and resources, the lack of communication processes in order to share patient information in a consistent and timely manner, and infrastructure issues such as sufficient office time to provide SCI patients with best health care practices resulting in substandard attention. The social determinant of transportation prevented timely and humane care to individuals who either had to navigate getting to appointments on their own or experience physical and emotional exhaustion from long and circuitous routes on a mobility bus. A single site or co-location of allied health professionals was expressed as a part solution to the transportation barrier. Lastly, some of the participants advocated for knowledge gaps to be partially assumed by patients under the auspices of empowerment through self-management.

In contrast to previous research conducted in this area, we intentionally reviewed our findings collected from medical professionals and rehabilitation and community service key informants through a social disability lens (Shakespeare, 2013) as an innovative way to look differently into this issue that continues to persist, hoping to open up new avenues of understanding of these barriers and promote dialogue. By analyzing medical model findings through a social disability lens, that purports disability is caused by the way society is organized (Goering, 2015), we hoped to identify where the challenges lie that prevent or impede the research to practice transfer. We acknowledge that while overlap exists between social and medical models, we take up the social model strategically when it is important to acknowledge the shaping role of social structures, or the resistance and self-advocacy of disabled people. This also reflects our current standpoint of inter-professional practice involving family physicians, nurses, social workers, marriage and family therapists, chiropractor and occupational therapy.

Firstly, what we found is a healthcare delivery infrastructure informed by the medical model that prevents adequate time for office visits, does not provide accessible on site specialized equipment, is lacking regarding sufficient knowledge and physician training for new and seasoned physicians alike and offers few clinical guidelines that are current and patient informed. All these challenges are accentuated in rural areas, when individuals with SCI must travel significant distances with great inconvenience to only receive suboptimal care at best. From the perspective of rehabilitation key informants, the current medical practice milieu is further compromised by a limited knowledge of community services by family physicians leaving persons with SCI in a space of fragmented or poorly coordinated care once discharged home from rehabilitation programs. Generally speaking these barriers experienced by patients with SCI are similar to those of individuals with other conditions resulting in physical disabilities, such as physically accessing primary care medical offices and knowledgeable care providers (Morrison et al., 2008; McColl et al., 2012; McMillan et al., 2016). Our findings are consistent with other studies that report individuals with SCI do indeed receive suboptimal primary care (Stillman et al., 2014; Morrison et al., 2008; McColl et al., 2012). Care gaps and barriers as identified by family physicians and rehabilitation key informants are consistent with those identified elsewhere (McMillan et al., 2016; Morrison et al., 2008) and highlight the continuation of the medical model that informs disability healthcare. Viewing these findings through the framework of Klein and Knight's (2005) organizational factors offers a lens in which to understand the barriers mentioned. For example, our finding of practitioner knowledge deficits combined with the absence of an accessible infrastructure (office design, accessible equipment and transportation) reflects factors one, three and five; quality and quantity of training, enough funding to support change and the leadership to spearhead such initiatives. Likewise, some physicians felt low caseload numbers did not warrant seeking the professional development required to be proficient in this specialized area of care.

From a social disability lens (Shakespeare, 2013) it would be simplistic however to suggest that the individual physicians and rehabilitation key informants interviewed in this study are responsible for failing to provide optimal care for individuals with spinal cord injury. It was evident in our study that a high level of compassion exists among the majority of those interviewed toward wanting to provide better care for this population as reflected in the statement, "*we are willing to really commit to caring for someone with spinal cord injury.*" That

said, many of the suggestions regarding how to improve the situation remained within an individualistic domain, placing the onus of change on the patient as in “[it would] *be extremely helpful if patients had skills or supports to come to effectively self-manage.*” Similarly, the low incidence of SCI patients within a physician caseload was stated by 92% as reason for not seeking continuing education regarding knowledge and skill set specific to SCI. This statistic speaks to perhaps unrealistic expectations placed upon the practitioner in a solo practice or small group practice who must balance between competing demands of an increasingly and more complex patient roster, budget restrictions, bureaucratic professional regulatory systems and high compassion fatigue (Carrieri et al., 2017). Additionally, the anatomical complexity specific to SCI patients and the multiple levels of care needed for recovery at the tertiary, primary, rehabilitative and community level can be overwhelming to physicians as reflected by the statement “*There’s no way that the average physician is going to be able to support somebody [with SCI].*”

In this way the medical model that continues to dominate both practice and medical training may not be working well for either physician or patient. It may also explain why research findings are slow to find their way into clinical guidelines and protocols reflecting Klein and Knight’s (2005) factor of leadership as a prerequisite for change. A study that explored physician attitudes toward women with mobility impairment (Joseph, Saravanabavan, & Nisker, 2018) suggests that if physicians were educated in a social model of disability, rather than the current medical model, a more holistic understanding of how “the social and physical environments are the etiologies that cause barrier to equal access” (p. 93). Extending this argument to the Klein and Knight model would mean revisiting the epistemological underpinning and pedagogical practices of medicine from that of solely a study of pathology to one of social and health equity across all populations.

New Ways of Working and Learning

While gaps related to knowledge and delivery were confirmed by family physicians and rehabilitation key informants in this study, what was gleaned and emerged from the data of greater importance is why this information is slow to move into practice and what moving ahead might look like. While barriers such as a lack of time, knowledge and involvement due to the small number of patients with SCI within physician caseloads, the absence of examination tables,

lengthy wait times for physiatrists or poor integration of community resources are reasonable reasons for the slow uptake into clinical practice, we suggest that these are symptoms of larger structural issues. We wonder how outcomes might be different if institutions of higher education adopted an epistemological shift, by moving to a social model of disability and away from the medical one that dominates both attitudes and practice. For example, while the identified barriers to change in this study reflect the organizational ones suggested by Klein and Knight (2005), we propose that larger structural attitudes prevail that continue to inform how medicine is delivered and aspects of power are reproduced within practice culture.

The social disability model is a response to the medical model and posits the experience of disability is socially constructed and reinforced through different systems, including those of health and education (D'Alessio, 2011). Physicians and authors Joseph and Nisker (2018) agree and put forth the argument that physicians would approach patients with disabilities differently if critical disability studies were part of medical education. Likewise, in an article published in the *Lancet*, Shakespeare and colleagues (2009) state “*curricula medicalise disability [and] fail to take a holistic view of health*” (p. 1815). If however, a holistic perspective was adopted, or what Hutchinson (2014) refers to as “*whole person care*” (p.4) it would mean a commitment by physicians and rehabilitation providers to intentionally work toward active patient collaboration with health and healing as an outcome (Hutchinson, 2014). Also referred to as “participatory medicine” (Dobkin, 2014) physicians who practice this way create time for the patient’s experiential knowledge related to their disability to be shared and become a regular or normal part of the office visit. Proponents of this approach challenge the traditional argument of being too time consuming, instead stating “*it actually takes less time [because] the physician grew to appreciate and more deeply understand their patient in ways that was not always evident*” (p. 84). If patient informed or participatory medicine speaks to a new paradigm of practice in which patients experience increased involvement and partnership informed care, then several initiatives are worth noting.

A number of resources and tools exist to build knowledge on the care of persons with SCI. Canadian resources include Caring for Persons with Spinal Cord Injury (<http://eprimarycare.onf.org/>) and Actionable Nuggets (www.actionnuggets.ca), that provide important information needed to assess and manage key SCI-related complications such as neurogenic bladder and bowel, and autonomic dysreflexia. The Spinal Cord Injury Rehabilitation

Evidence (SCIRE) website (<https://www.scireproject.com/>), provides a critical review of the existing resources and literature on many SCI related topics. While these resources provide valuable knowledge for managing SCI care, access to point-of-practice tools and practice guidelines is highly valued by physicians (McMillian et al., 2016). One such tool is the Preventative Care Checklist Form for use during health check-ups (Dubey & Glazier, 2006; Duerksen, Dubey & Iglar, 2012). The Spinal Outreach Service Questionnaire (SOS-HQ) lists key questions to ask for preventive care screening and to identify new health concerns (Mann, Middleton & Leong, 2007). Similarly, a SCI toolkit was recently created consisting of 33 outcomes measures aiming to improve the identification of best practice protocols and to better monitor and proactively intervene regarding health issues associated with spinal cord injury (Authors, 2018). A similar tool patient informed self-management tool was administered to patients with SCI in primary care settings with results indicating a high level of interest and desire to be involved in decisions impacting their healthcare (McMillan & Milligan, 2010). Actively incorporating the few existing toolkits, especially the patient informed toolkit, for individuals with SCI into primary care has the potential to create whole person care between patient and expert informed protocols for this population, and in doing so, reflect the changing landscape of healthcare. Making such toolkits digitally available in patient e-portals would augment patient involvement by ensuring up to date or changing health information is readily accessible. It can also address the discrepancy identified in this study between physicians and patients of what is of importance regarding health issues and making patient identified concerns more central.

Another initiative concerns timely access and exchange of information between family physicians and rehabilitation providers. Initiatives such as electronic-consultations using secure email or web-based requests, may provide an effective mechanism for timely access to specialist advice. E-consultation has been used for a variety of health conditions with success (Liddy, Rowan, Afkham, Maranger, & Keely, 2013), however little attention has been paid to its use with SCI. Future research should explore the use of e-consultation, which would serve to build capacity for SCI in a primary care setting and to support improved care integration and coordination across sectors (rehabilitation, community, acute care, primary care) and avoid the current fragmentation of services.

Lastly, the format in which participatory medicine assumes to address gaps within health

delivery is important to comment on. Both the literature and our study identified that the preferred physician method for greater knowledge dissemination regarding SCI was through passive dissemination. The top three preferences identified by our participants were all passive modalities; education lectures in their geographical location, education lectures delivered to their individual practice and education lectures delivered via videoconferencing. However, there is evidence within health literature that passive knowledge translation activities alone are inadequate for changing practitioner behaviour (Bero et al., 1998). Passive activities include traditional didactic seminars, lectures or print material in the form of guidelines and were the preferred modalities by the physicians in this study. Returning to Klein and Knight's (2005) framework, the lack of strong leadership advocating for active teaching and knowledge dissemination methods may be a reason why physicians continue to prefer passive knowledge activities. Despite the Canadian Institutes of Health Research advocating for active activities that focuses on experiential learning and observation with a clinical space to practice new skill sets as a method to transfer knowledge to practice (Canadian Institutes of Health Research, 2014) our findings suggest that this has yet to happen. This again suggests that the criteria of leadership for overarching pedagogical change is needed yet absent. To this end, we advocate for a shift to a social disability paradigm so content developed by and offered from individuals living with SCI can make visible the range and depth of mobility challenges. We also advocate such lived experience is legitimized as knowledge through remuneration, stepping away from the current norm that perceives this unpaid work as volunteering.

Study Limitations

There are several limitations to this study. The response rate for the physician questionnaire was low, perhaps reflecting lack of interest if they had few patients with SCI in their practice. Although the sample size for this study is small, the interviews were completed to the point of saturation (little or no information was gathered in the final interviews conducted). The achievement of saturation with the existing sample size was influenced by the nature and narrow focus of the topic, with SCI being a low prevalence condition, the quality of the data obtained, sample specificity, and our analytic strategy (Malterud, Siersma, & Guassora, 2016; Morse, 2015). Moreover, triangulation of the interview and questionnaire data served to verify and enhance the credibility of the findings across methods (Creswell, Fetters, & Ivankova, 2004).

Lastly, readers may raise the question of representiveness in terms of the small sample size recruited for this study. Crouch & McKenzie (2006) suggest that sample size and representativeness “have little bearing” on the quality of the information collected, especially if the phenomena studied has yet to yield significant impacts within the field (p.483). This is certainly the case for SCI practice contexts where sub-optimal healthcare for SCI patients continues to be the norm. While this study gained us a greater understanding of opportunities for improving primary care for individuals with SCI from the perspective of healthcare providers, further research is needed to obtain the perspectives of individuals living with SCI.

Conclusion

This study contributes to the identification and understanding of barriers and solutions for the care of individuals living with SCI from the perspectives of physicians and rehabilitation. Key informants from a social disability lens. While our study confirms previously identified barriers, it extends the literature by raising the question of why future health providers are not supported with curriculum that focuses more on the structural biases that frame attitudes and practices toward individuals with spinal cord injury. Until educational and political systems are willing to shift the paradigm toward a different view of disability, ensuring accessible examination equipment and remuneration for longer office visits for example, there is likely to be a slow translation of research findings into clinical practice. Until this happens, equitable health practices will continue to elude this vulnerable population.

Conflict of Interest Statement

The authors declare that they have no competing interests.

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