

## **The Application of Telehealth Among Community-dwelling Adults with SCI**

**THE APPLICATION OF TELEHEALTH AMONG COMMUNITY-DWELLING  
ADULTS WITH SPINAL CORD INJURY**

By SHAGHAYEGH MIRBAHA, B.A.

A Thesis Submitted to the School of Graduate Studies in Partial Fulfillment of the Requirements  
for the Degree Master of Science in Rehabilitation Sciences

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M.Sc. - S. Mirbaha; McMaster University - Rehabilitation Science

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AUTHOR: Shaghayegh Mirbaha, B.A. (McMaster University)

SUPERVISOR: Dr. Julie Richardson, Ph.D.

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## **LAY ABSTRACT**

The objective of this thesis was to identify telehealth service models and explore essential characteristics and potential functions of a virtual clinic to enhance the provision of care for persons with SCI who live in their communities. Study One was a scoping review of the literature to identify, describe, and compare models of telehealth services in persons with SCI living in the community. Study Two is a qualitative study using the interpretive description (ID) approach that consulted with various healthcare professionals to identify what they regard as the feasible, essential characteristics, and potential functions of a virtual clinic for persons with SCI living in the community. The information gained from these studies could be used to inform various stakeholders involved in developing future virtual clinics for persons with SCI.

## **ABSTRACT**

Spinal cord injury (SCI) is a complicated disorder that leads to considerable morbidity and cost burden on the health system, primarily due to the wide range of long-term secondary complications that frequently occur following SCI. Many SCI-associated secondary complications could be prevented or managed with improved access to care for individuals with SCI in the long term who live in the community. However, accessibility to community services for SCI has been further limited when considering accessibility barriers and constraints from the Covid-19 pandemic. Thus, applying telehealth services is one optimal solution for alleviating barriers to accessing rehabilitation services for community-dwelling adults with SCI. This thesis aimed to identify telehealth service models and explore essential characteristics and potential functions of a virtual clinic to improve the provision of care for community-dwelling adults with SCI.

Study One was a scoping review of the literature to identify, describe, and compare models of telehealth services in community-dwelling adults with SCI. Study two is a qualitative study using the interpretive description (ID) approach that consulted with various stakeholders to identify what they regard as the feasible, essential characteristics, and potential functions of a virtual clinic for community-dwelling adults with SCI.

Findings from these two studies indicated that telehealth might offer an efficient and effective option for health service delivery for community-dwelling individuals with SCI, ensuring continuity of rehabilitation, follow-up after hospital discharge, and management of potential secondary complications following SCI. Findings suggest the benefits of virtual care in improving access over the long term, particularly for those living in rural areas. Additionally, results highlighted the need for hybridized models of care and the uptake of multidisciplinary

approaches within the virtual healthcare system to create efficient care pathways, leading to the continuum of care for community-dwelling adults with SCI. The information gained from these studies could be used to inform policymakers, HCPs, and stakeholders involved with SCI rehabilitation when establishing a virtual clinic for patients with SCI.

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## **LIST OF ABBREVIATIONS**

SCI	Spinal Cord Injury
ID	Interpretive Description
TSCI	Traumatic Spinal Cord Injury
NTSCI	Non-Traumatic Spinal Cord Injury
ASIA	American Spinal Cord Injury Association
VIP4SCI	Virtual Integrated Platform for Spinal Cord Injury
LTPA	Leisure-Time Physical Activity
PA	Physical Activity
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
TeleSCI	Telespinalcordinjury
HCPs	Healthcare Professionals

## DECLARATION OF ACADEMIC ACHIEVEMENT

This thesis is structured as a “sandwich thesis”, comprised of two individual manuscripts prepared for peer-reviewed publication and linked by an introduction and a discussion. The papers within the thesis were formatted following the journal requirements to which they will be submitted.

Shaghayegh Mirbaha contributed to the elements of these studies, including conception, design, data collection, analysis, writing of all manuscripts, and submitting them to peer-reviewed journals for their publication, with collaboration from the supervisor, Dr. Julie Richardson, and the supervisory committee, Dr. Ada Tang, and Dr. Jenna Smith-Turchyn. The initial draft of the Introduction (Chapter 1) and discussion (Chapter 4) has been primarily written by Shaghayegh Mirbaha, with feedback from the Supervisor, Dr. Julie Richardson, and review from the supervisory committee, Dr. Ada Tang and Dr. Jenna Smith-Turchyn. For the manuscripts (Chapter 2), the first author, Shaghayegh Mirbaha, contributed to the study’s conception, design, data collection and analysis, with collaboration from all co-authors (Dr. Julie Richardson, Dr. Ada Tang, Dr. Jenna Smith-Turchyn, and Ashley Morgan). Screening of articles were completed by Shaghayegh Mirbaha and Ashley Morgan, under the supervision of Dr. Julie Richardson. Contents of this chapter were written by Shaghayegh Mirbaha with preliminary edits from Dr. Julie Richardson, and review from all co-authors. For the second manuscript (Chapter 3), the first author, Shaghayegh Mirbaha, contributed to the study’s conception, design, data collection and analysis, with collaboration from all co-authors (Dr. Julie Richardson, Dr. Ada Tang, and Dr. Jenna Smith-Turchyn). Shaghayegh Mirbaha applied for the Study’s ethics approval with the supervision of Dr. Julie Richardson. Content of this chapter were written by

M.Sc. - S. Mirbaha; McMaster University - Rehabilitation Science

Shaghayegh Mirbaha with preliminary edits from Dr. Julie Richardson, and review from all co-authors, assisting with developing interview guide and interpretation strategies.

**CHAPTER ONE:**  
**INTRODUCTION AND LITERATURE REVIEW**



## **1.1 Outline Of Thesis**

The primary purpose of this thesis was to identify the available models of telehealth services to improve the provision of community-based care in individuals living with spinal cord injuries (SCI). The thesis explores what are the feasible, and essential characteristics, and potential functions of a virtual clinic for community-dwelling adults with SCI. This thesis work is part of a funded research program to develop a virtual clinic for community-dwelling adults with SCI in Hamilton, Ontario. The introduction chapter (Chapter 1) includes a literature review which discusses; (1) the epidemiology and lifetime cost-of-illness of SCI, (2) secondary long-term complications after SCI, (3) healthcare utilization, follow-up care and rehabilitation for community-dwelling adults with SCI, (4) application of telehealth service delivery models in persons with SCI, and (5) limitations in the current literature for telehealth interventions used to prevent, manage, or treat chronic secondary complications in community-dwelling adults with SCI, directing the discussion in this thesis paper. This thesis consists of two accompanying studies. Study One is a scoping review (Chapter 2) to review the literature and identify, describe, and compare models of telehealth services in community-dwelling adults with SCI. Study two is a qualitative study using an interpretive descriptive (ID) approach that aimed to consult various stakeholders to identify what they regard as the feasible, essential characteristics, and potential functions of a virtual clinic for community-dwelling adults with SCI. In the discussion chapter (Chapter 4) of this thesis, the implications for future research and the combination of the findings from study one and study two were provided to inform the policymakers, healthcare professionals, and local and national stakeholders engaged in implementing and establishing a virtual clinic for the SCI population.

## **1.2 EPIDEMIOLOGY OF SCI**

### **1.2.1 Definition of SCI**

The spinal cord enables sensory and motor signals to travel through this main conduit, connecting the brain, the center of the nervous system, to the rest of the body<sup>1-3</sup>. The spinal cord and peripheral nervous system transmit all the neural signals involved with muscle contraction, cardiac rhythm, pain, and other voluntary and involuntary body functions.<sup>2</sup> Spinal cord injury (SCI) is an immediate obstruction to the neural tissue within the spinal canal, which affects the conduction of sensory and motor messages throughout the site(s) of the lesion(s) and the autonomic nervous system.<sup>1</sup> As a result, any damage to the spinal cord inhibits or decreases the transmission of these neural signals between the brain and the periphery, impacting movement, sensation, and involuntary functions.<sup>1</sup>

### **1.2.2 Overall Incidence & Prevalence**

According to the World Health Organization, every year, between 250,000 and 500,000 individuals sustain an SCI.<sup>4</sup> The majority of SCI's are due to avoidable traumatic injuries, such as vehicle accidents, falls, or violence.<sup>4</sup> Although there is no definite estimate of SCI global prevalence, the annual global incidence rate is anticipated to be 40 to 80 cases per million population.<sup>4</sup> Up to 90% of these cases are due to traumatic injuries.<sup>4</sup> Approximately 86,000 people live with spinal cord injury (SCI) in Canada.<sup>5</sup> There are an estimated total of 4,528 new cases of SCI each year, where 1,786 cases are due to traumatic SCI (TSCI).<sup>5</sup> The remaining are consequences of non-traumatic causes (NTSCI) such as infections and diseases (i.e., cancer).<sup>5,6</sup> Over the next two decades, cases of SCI are expected to rise from the current estimate of 86,000 Canadians living with SCI in 2010 to 121,000 persons with SCI by 2030.<sup>5</sup>

### **1.2.3 Etiology of SCI**

The causal mechanisms leading to the SCI are classified into two types: traumatic (TSCI) and non-traumatic (NTSCI).<sup>6,7</sup> TSCIs are most frequently in consequence of traumatic events such as falls, motor vehicle accidents, and violence.<sup>7</sup> NTSCI is usually a result of diseases, including spondylosis, infections, or cancer.<sup>7</sup> Studies comparing patients with TSCI and NTSCI indicate that TSCI often appears in younger male individuals, while older female adults with more comorbidities are at higher risk of NTSCI.<sup>6,7</sup> The incidence of TSCI in Canada is estimated to be 1785 cases per year and the remaining 2742 new cases of SCI per year are predicted to be a consequence of diseases and other NTSCI.<sup>5</sup> In Canada, of the estimated total prevalence of SCI (86,000 persons), approximately 44,000 people (51%) sustained a sustained TSCI.<sup>8</sup> Both age-specific prevalence and incidence rates of SCI in Canada demonstrate that TSCI is more common in younger age groups while NTSCI is concentrated in older populations.<sup>5</sup> TSCI is more common in younger adults as they are at higher risks for motor vehicle accidents and violence.<sup>5,6</sup> In contrast, NTSCI is more prevalent in older adults as the tissues and vital organs degenerate progressively with the ageing process.<sup>5-7</sup> Due to Canada's rapidly aging population, the mean age of individuals who sustain SCI and the type of healthcare services required have changed.<sup>5</sup> In the coming decades, the cause and age group of people with SCI will shift from younger males who had motor vehicle collisions to older adults who experience falls.<sup>5</sup>

### **1.2.4 Types, Level, and Severity of Injury**

SCIs are classified based on the severity of the injury into two types of complete or incomplete injuries.<sup>15,16</sup> A complete injury is referred to as a full loss of motor and sensory functions.<sup>9,10</sup> Whereas partial preservation of motor or sensory function below the neurological level of injury and in the lower sacral regions is referred to as incomplete SCI. Additionally,

paralysis from an SCI can be denoted as either "Tetraplegia" or "Paraplegia".<sup>9</sup> The term tetraplegia, on occasions referred to as quadriplegia refers to impairment or loss of motor, sensory or autonomic function in the cervical segments of the spinal cord.<sup>9</sup> In a person with tetraplegia the impairment of function is seen in the arms and the trunk, legs, and pelvic organs.<sup>9</sup> In persons, who have paraplegia, arm function is preserved, but the trunk, legs, and pelvic organs may be affected, depending on the severity of the damage.<sup>9,10</sup> The clinical presentation of SCI is highly varied depending on the completeness of the injury to the spinal cord, affecting the transmission of all or partial neural signals across the site(s) of the lesion(s).<sup>9,10</sup>

American Spinal Injury Association (ASIA) Impairment Scale is commonly used to classify SCI, determining the presence and degree of motor, sensory, and autonomic functioning below the level of the injury.<sup>1,9,10</sup> According to the latest version of the ASIA released in 2011, SCI is classified as either complete (ASIA) or incomplete (AIS-A, B, C, D, or E) based on the severity of injury varying from letter A (complete injury with loss of motor and sensory function) to letter E (normal motor and sensory examination).<sup>1</sup> *Table 1* lists the components of the ASIA scale in detail.<sup>9</sup> As shown in *Table 1*, a significant association exists between the functional status and severity (i.e., completeness) and the level of injury.<sup>9</sup> As a consequence of injury, the function of spinal cord is disrupted distal to the level of the injury.<sup>9</sup>

**Table 1.** American Spinal Injury Association scale for spinal cord injury

ASIA Impairment Scale (AIS)*	
Grade	Type and Description of Injury
ASIA-A	Complete – There is no sensory or motor function preserved in the sacral segments S4-S5
ASIA-B	Sensory incomplete – sensory function preserved but motor deficit below the neurological level, including the sacral segments of S4-S5. No motor function is protected more than three levels below the motor level on either side of the body

ASIA-C	Motor incomplete - motor function is protected below the neurological level. More than half of the muscles below the neurological level of injury have strength lower than 3/5 (muscle grade 0-2)
ASIA-D	Motor incomplete – motor function is preserved below the neurological level. At least half of the muscles below this level have a muscle grade $\geq 3$
ASIA-E	Normal – sensation and motor function as assessed by the ISNCSCI in all segments are graded normal. The AIS degree is E for those patients who had pre-existing deficit. An individual with no spinal cord injury does not get an AIS degree.

*Note.* Adapted from “Rehabilitation of Spinal Cord Injuries” by Nas K, Yazmalar L, Şah V, Aydın A, Öneş K, 2015, *World J Orthop*, 6, p. 6-18.

### 1.3 Secondary Long-Term Complications After SCI

A SCI compromises independence and physical functioning and results in several long-term secondary complications.<sup>11-13</sup> The most frequent complications after SCI include pressure ulcers (10.2%–30%),<sup>14</sup> urinary tract infections (22%),<sup>15</sup> psychosocial problems (40%),<sup>16</sup> chronic pain (11% to 94%),<sup>17</sup> respiratory complications (36%–83%)<sup>11</sup>, cardiovascular disorders (17.1%),<sup>18</sup> osteoporosis (21.5%)<sup>19</sup> and bone fractures (7.4%)<sup>19</sup>. Therefore, persons with SCI may experience considerable impairments in various aspects of their life. Globally, individuals with SCI are two to five times at higher risk of dying prematurely than those without SCI.<sup>4,20</sup> Cardiovascular diseases and cancer are the two highest mortality factors in persons with SCI<sup>21,22</sup> but recent studies have shown pneumonia and other respiratory problems are also a frequent cause of mortality<sup>21,24</sup>. Urinary tract issues and renal failure were the primary causes of death in the 1950s.<sup>21,23</sup> Weaver et al., found that in United States, the 60-day mortality rate for pneumonia after acute respiratory complications was 7.9% over a total of 8700 outpatient visits in veterans with SCI.<sup>24</sup> The study by Strauss *et al.* found that there were higher mortality rates for persons with higher levels of injury, particularly among those with high cervical injuries and those with complete (ASIA A) injuries compared to persons with lower levels and incomplete (ASIA B or

C) injuries, respectively.<sup>21,25</sup> Mortality risk rises with the level and severity of the injury<sup>4</sup>, with a higher rate of death associated with the people with SCI in low- and middle-income countries.<sup>4,20</sup> These secondary sequelae may negatively impact a patient's functional independence, life expectancy and quality of life.<sup>11,13</sup> They may further cause a delay in community reintegration, increased rate of rehospitalizations, loss of employability, limitations in completing daily living activities, and lead to sexual dysfunction.<sup>11</sup>

Persons with SCI undergo therapy for many years, beginning with acute care and early surgical treatments immediately after the injury, followed by treatment for chronic sensory, motor, and autonomic dysfunction and eventually lifelong management of the condition in the community-based settings, such as individual's homes, homecare centres, and public health units.<sup>11,13,26</sup> A study conducted to evaluate the unmet needs of persons with SCI during the first-year post rehabilitation in Quebec, Canada, indicated that needs regarding emotional and psychological support, employment, and education services are often unmet.<sup>27</sup> Canadian data from the Rick Hansen Spinal cord Injury Registry (renamed the Praxis Spinal Cord Institute) from 2014-2015 estimated that the average length of stay in acute care and for rehabilitation after SCI was 37.8 and 99.2 days, respectively.<sup>28</sup> Approximately 80% of persons with incomplete SCI can restore their ambulatory capabilities after participation in rehabilitation programs.<sup>29</sup> These inpatient and outpatient rehabilitation programs and processes aim to improve physical functioning, decrease secondary morbidity, and improve health-related quality of life.<sup>11,12,26</sup>

#### **1.4 Healthcare Utilization in Persons with SCI**

SCI is considered one of the most devastating kinds of injury, which impacts one's health and creates a considerable economic burden for the family, caregiver, and society.<sup>26</sup> In Canada, each year, the projected lifetime economic cost of SCI varies from \$1.5 million to \$3.0 million

per individual, depending on whether the patient has partial paraplegia or total tetraplegia.<sup>5</sup> SCI contributes to significant functional and financial burden and generates life-threatening issues for the patient's mental health and social stability.<sup>5,11,12,26</sup> Family caregivers play a crucial role in assisting, and often assume most or all of the responsibilities of caring for individuals with SCI.<sup>30</sup> This considerable responsibility may have several physical and emotional impacts for the family caregiver, including caregiver's inability to balance responsibilities at home and work environment, neglecting their own health, and less participation in society.<sup>30</sup> Considering SCI's significant health, economic, and social burden on the persons, caregivers, and society, early prevention, detection, and treatment are crucial for limiting these sequelae and enhancing survival, health-related quality of life, and community reintegration.<sup>11-13,26</sup>

Healthcare utilization in persons with SCI is frequently influenced by the accessibility of care, availability of specialized care and provider's knowledge about SCI-specific care, or regionally distinct patient preference.<sup>12,31,32</sup> People with SCI who remain in their homes post-injury may face several barriers to accessing healthcare services.<sup>11</sup> These barriers include long distances from healthcare facilities and lack of transportation, physical obstacles such as inaccessibility of physician offices, attitudinal barriers, shortage of family physicians, and primary care physicians' lack of knowledge about SCI and managing associated secondary complications such as bowel and bladder issues, skin breakdown, spasticity, and respiratory complications.<sup>11,12,31-33</sup> A study on geographical proximity and healthcare utilization in veterans with SCI showed that longer travel distances to healthcare facilities reduced the utilization of in-patient hospital care and outpatient clinics' services in persons with SCI.<sup>12</sup> A further retrospective cohort study describing the physician utilization patterns among adults with traumatic SCI in

Ontario, Canada, indicated that higher emergency department visits may reflect limited accessibility to primary care services for persons with SCI in rural regions.<sup>34</sup>

Following discharge from acute care facilities and rehabilitation clinics, primary care providers, known to be the first point of contact between a patient and the Canadian healthcare system, are responsible for delivering essential medical care to persons with SCI who live in their communities.<sup>9,13</sup> Due to the relative low prevalence of persons with SCI within the population, there are generally few persons with SCI within a primary care practice.<sup>13</sup> Specifically, in Canada, it has been reported that there would only be 1 or 2 persons with SCI within the average family medicine caseload.<sup>31</sup> As a result, family physicians rarely have the chance to develop knowledge and expertise about the speciality care required to manage persons with SCI.<sup>13</sup> In accordance with Cox *et al.*<sup>35</sup> and McColl *et al.*<sup>15</sup>, 81% of community-dwelling adults with SCI reported limited primary care provider knowledge and expertise, therefore, inadequately being treated in the primary care settings.<sup>31,35</sup> Donnelly *et al.* found that in Canada, 99% of persons with SCI prefer receiving their routine rehabilitation follow-up care from spinal injuries specialists.<sup>36</sup> In geographic areas where primary-care services are scarce, hospital emergency departments are accessed by persons with SCI in place of primary-care services.<sup>12</sup> The literature reports higher utilization rates of primary care services, outpatient rehabilitation clinics, and in-patient hospital services among community-dwelling adults with SCI than the general population.<sup>12</sup> According to Dryden *et al.*<sup>37</sup>, in Canada, persons with SCI need 30 more hours of home-care services, were 2.7 times more likely to visit a physician, were re-hospitalized 2.6 times more frequently, and stayed 3.3 more days in the hospital compared to people without SCI.<sup>34,37</sup> Research suggests that inadequate access to healthcare services in primary care or



outpatient settings may lead to a high rehospitalization rate for non-inevitable long-term secondary complications.<sup>11,12</sup>

### **1.5 Follow-up Care and Rehabilitation**

Due to the high prevalence of secondary complications following SCI, rehabilitation inpatient and outpatient teams are required to expand their role in follow-up care for community-dwelling adults with SCI by advising primary care professionals on SCI-associated complications and their potential management strategies and treatment plans.<sup>15,19</sup> In the first few months after discharge, follow-up examinations aim to offer specialist medical care and regular ambulatory consultations to individuals with SCI while transitioning into outpatient settings.<sup>38,39</sup> These regular check-ups and follow-up visits are held to identify upcoming complications at the appropriate time and to maintain rehabilitation processes concerning physiotherapy, occupational therapy, and social and professional reintegration of the individual with SCI.<sup>39</sup> Rehabilitation follow-ups include examination and assessments of function and functional related impairments, psychosocial and financial aspects, and home adaptations of the individuals with SCI.<sup>39</sup> Over the long term, comprehensive follow-ups are performed to detect the most common secondary complications such as pressure injuries, respiratory complications, bowel and bladder issues, and psychological disorders.<sup>39</sup> During the follow-up visits, providers monitor recommendations' adherence and resolve the questions that may come across for community-dwelling adults with SCI.<sup>38,39</sup> A systematic review<sup>13</sup> identified five different methods of follow-up care delivery, including telehealth, outpatient consulting, home visits, case management, and mixed types of follow-up care encompassing a combination of the listed methods.<sup>13</sup> This systematic review<sup>13</sup> found that the majority of the available follow-up care programmes for persons with SCI aim to

prevent and/or treat secondary impairments, promote well-being, improve health-related quality of life, and community reintegration.<sup>9,13</sup>

## **1.6 Telehealth for Persons with SCI**

Telehealth has been a significant advancement in medicine.<sup>40</sup> It can be interpreted as “the delivery of information and health-related services via telecommunication technologies.”<sup>41</sup> In Austria in 2016, an international panel of leaders in telehealth and SCI gathered at the International Spinal Cord Society (ISCoS), coining the term “telespinalcordinjury”, or teleSCI.<sup>11,12</sup> The terms teleSCI and telehealth for individuals with SCI are used interchangeably throughout the literature.<sup>11,12</sup> In recent years, telehealth technologies have risen in importance, with healthcare services being directly available to individuals with SCI for concerns, including upper respiratory and urinary tract infections.<sup>42</sup> The present global COVID-19 pandemic highlighted the importance of telehealth, facilitating the continuation of primary healthcare services for persons who need supportive care.<sup>43</sup> The application of telehealth technologies enables persons with SCI to overcome issues of transportation and long distances to the healthcare facilities.<sup>40,41</sup> Evidence on existing effectiveness and satisfaction data indicated that telehealth is advantageous and generally viewed as satisfying to individuals with SCI.<sup>44,45</sup> In a systematic review and qualitative synthesis of randomized trials in the most recent decade on the effectiveness of telehealth for individuals with SCI, about 80% of the included studies indicated considerable improvements in function, self-management, and quality of life, as well as high satisfaction with telehealth modalities.<sup>45</sup>

In Canada, several organizations exist to support research and improve the quality of life for persons with SCI, including The Centre for Family Medicine Mobility Clinic, The Ontario Neurotrauma Foundation, The Risk Hansen Institute (renamed The Praxis Spinal Cord Institute),

and SCI Ontario.<sup>46</sup> All these organizations are established with a general objective of enhancing access to quality SCI care, including both primary and community care and increasing SCI research to develop strategies more adequately addressing issues that persons with SCI may face.<sup>46</sup> Two examples of virtual programs and services developed by these SCI organizations to improve SCI care include the SCIO Connect Peer Program and the VIP4SCI.<sup>47,48</sup>

First, SCIO Connect Peer Program provides peer support to persons with SCI.<sup>47</sup> This program aims to match newly injured patients and their family members with individuals who have lived experience with an SCI, assisting the patients to gain more confidence as they gain detailed information and a bigger picture of living with an SCI.<sup>47</sup> Peer mentors aim to inform persons with SCI about various SCI-related topics, including self-care, accessibility and housing, community resources, transportation, family relations, relationships, and employment opportunities. Peer mentors are also responsible for connecting the persons with SCI with other organizations that can provide various assistance.<sup>47</sup> This peer mentorship program offers services virtually with peer mentors contacting persons with SCI by phone, email, and video conferencing.<sup>47</sup> Various studies evaluate existing peer mentorship programs and provide a deeper understanding of the outcomes of these programs.<sup>49</sup> Sweet et al. (2021) conducted a qualitative study to gain a deeper understanding of the SCI peer mentorship programs delivered by Canadian community-based organizations and identified positive outcomes such as hope, engagement in daily and social activities, feeling understood, and an increase in self-confidence.<sup>49</sup>

Second, in November 2017, “Virtual Integrated Platform for Spinal Cord Injuries (VIP4SCI)” was established to address the issue of accessibility of care for persons living with SCI throughout Ontario, Canada.<sup>48</sup> Spinal Cord Injury Ontario, Toronto Rehabilitation Institute,

Center for Family Medicine in Waterloo, and Parkwood Institute in London, Ontario teamed up to develop this virtual healthcare platform allowing for more convenient communication between patients, primary care providers, SCI specialists, and social service providers.<sup>48</sup> Community-dwelling adults with SCI may benefit from the video-conferencing VIP4SCI, eliminating travel time and challenges with traveling for in-person routine healthcare.<sup>48</sup> However, in-home virtual consultations provided by these virtual platforms cannot resolve all types of medical needs patients may possess, such as non-routine check-ups where a primary care provider requires a physical examination.<sup>48</sup>

With increasing healthcare costs and a shortage of skilled personnel for in-person health-related services mainly due to the COVID-19 pandemic, more cost-efficient ways to provide follow-up care are being investigated, such as the use of telehealth interventions.<sup>50</sup> Telehealth services may be advantageous over in-person approaches for several reasons; (1) they are accessible to more individuals, especially those who live in rural areas away from urban healthcare facilities; (2) they can be administered concurrently to a more significant number of patients, and (3) may provide cost saving compared to traditional in-person approaches.<sup>43</sup> There are several reasons for using telehealth technologies in providing specialty care services addressing medical and rehabilitation needs for individuals with SCI. These rationale include extended distances to travel to receive SCI-related specialty care, lack of access to primary care services, higher costs for SCI care, and the adverse effect of shortened hospital stays on patients' health condition.<sup>40-43</sup>

### **1.6.1 Types of Telehealth Technologies**

Telehealth modalities can be categorized into “synchronous” and “asynchronous.”<sup>43,51</sup> Synchronous telehealth allows the communication between the patient and the provider to occur

in real-time.<sup>43,51</sup> With synchronous telehealth, both parties are required to be present simultaneously, communicating by video conference or audio or textphone conversations.<sup>43,51</sup> Asynchronous telehealth, also known as "store-and-forward telehealth," is an alternative approach to synchronous technologies, which allows for communication between the provider and patient without needing real-time information exchange through encrypted email or other messaging systems.<sup>51</sup> While there are quantitative studies exploring the effectiveness of telehealth technologies in improving secondary complications in community-dwelling adults with SCI,<sup>52-55</sup> some recent reviews investigate knowledge gaps about telehealth for persons with SCI. For example, one narrative review<sup>40</sup> and one scoping review<sup>56</sup> explored telehealth use and delivery models from rehabilitation to community, identifying outstanding knowledge gaps in the field of telehealth for SCI population. The narrative review categorized its findings based on the way teleSCI was provided (voice only, video plus voice, computer only, and robotic voice or video) and to whom the telehealth services were delivered (provider to provider for providers' communication and connection, provider to patients, store and forward also known as asynchronous, web-based treatments or real-time interactions, and interactive home monitoring).<sup>40</sup> The results of the scoping review identified several international healthcare systems defining models of care specific to the rehabilitation of persons with SCI, such as transitional rehabilitation models aiming for continuity of care when transitioning to the community, independent-living models or also known as self-managed care, and agency care models, where caregiving is delegated to healthcare professionals.<sup>56</sup> However, there remains a need to determine the overall status of telehealth for community-dwelling adults with SCI, extensively exploring the key features of existing telehealth services, the characteristics of the target population, and providing insights into the available literature, future directions and

considerations when applying telehealth for persons with SCI. Additionally, there are outstanding gaps in the identification of optimal characteristics of models of telehealth as well as features of a virtual clinic for community-dwelling adults with SCI from the healthcare professional's perspective. To our knowledge, there remains a need for a scoping review to explore the literature, providing an opportunity to identify key concepts, highlight knowledge gaps in the research, and types and sources of evidence to inform practice and policymakers involved with individuals with SCI. A recent study explored persons with SCI experiences and perceptions towards teleSCI services during the COVID-19 global pandemic in British Columbia, Canada.<sup>57</sup> However, there are no qualitative studies exploring healthcare professionals' views about the feasible characteristics and potential functions of a virtual clinic to address the rehabilitation needs of community-dwelling adults with SCI. A qualitative study was needed to gather in-depth insights as qualitative data are expressed in words, enabling researchers to understand concepts, thoughts, or experiences.<sup>58</sup> Such qualitative research using interpretive description methodology was undertaken previously to explore the stakeholder groups' perspectives on establishing a virtual clinic for patients with diabetes.<sup>59</sup> There is a need to synthesize both scoping review and qualitative evidence, informing stakeholders engaged in establishing a virtual clinic of care and ideal function and features of future virtual clinics for persons with SCI.

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**CHAPTER TWO:**  
**MODELS OF TELEHEALTH SERVICE DELIVERY IN ADULTS WITH**  
**SPINAL CORD INJURIES: A SCOPING REVIEW**

*\*This study has been submitted to the JMIR Rehabilitation and Assistive Technologies journal.*

Shaghayegh Mirbaha<sup>1</sup>, Ada Tang<sup>1</sup>, Jenna Smith-Turchyn<sup>1</sup>, Ashley Morgan<sup>1</sup>, Julie Richardson<sup>1</sup>

<sup>1</sup> School of Rehabilitation Science, Faculty of Health Science, McMaster University, Hamilton, Ontario, Canada

Corresponding Author:

Julie Richardson,

School of Rehabilitation Science

McMaster University

1400 Main Street West

Hamilton, ON

Canada

Email: jrichard@mcmaster.ca

## 2.0 ABSTRACT

*Background:* In Canada, approximately 86,000 people live with spinal cord injury (SCI), and there are an estimated 3,675 new cases of traumatic or non-traumatic etiology per year. Most people with SCI will experience secondary health complications such as urinary and bowel issues, pain syndrome, pressure ulcers, and psychological disorders, resulting in severe chronic multimorbidity. Moreover, people with SCI may face barriers in accessing healthcare services such as lack of transportation, physical obstacles, and lack of preventative health screenings and primary care physician's expert knowledge regarding secondary complications related to SCI. Telehealth, defined as the delivery of information and health-related services via telecommunication technologies, may help address some of these barriers and indeed, the present global COVID-19 pandemic has emphasized the importance of integration of telehealth in healthcare systems. As a result of this crisis, healthcare providers have increased the usage of telehealth services, providing health services to individuals in need of community-based supportive care. However, the evidence on models of telehealth service delivery for adults with SCI has not been previously synthesized.

*Objective:* The purpose of this scoping review was to identify, describe, and compare models of telehealth services in community-dwelling adults with SCI.

*Methods:* This scoping review follows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for scoping review guidelines. Studies published between 1990 to February 1<sup>st</sup>, 2022, were identified by searching Ovid Medline, Ovid Embase, Ovid Psycinfo, Web of Science, and CINAHL databases. Two investigators screened papers with specified inclusion criteria. Included articles focused on identifying, implementing, or evaluating telehealth interventions, including primary healthcare services and self-management services delivered in the community and home-based settings. One investigator performed a full-text

review of each article, and data extraction included: (a) study characteristics, (b) participant characteristics, (c) key characteristics of the intervention/programs/ services, and (d) outcome measures and results.

*Results:* A total of 57 articles reported telehealth services used for preventing, managing, or treating the most common secondary complications and consequences of SCI, including chronic pain, low physical activity, pressure ulcers, and psychosocial dysfunctioning. Where evidence exists, improvements in community participation, physical activity, and reduction in chronic pain, pressure ulcers, and psychosocial problems following SCI were demonstrated.

*Conclusion:* Telehealth may offer an efficient and effective option for health service delivery for community-dwelling individuals with SCI, ensuring continuity of rehabilitation, follow-up after hospital discharge, and early detection, management, or treat potential secondary complications following SCI. We recommend further research to evaluate the effectiveness of telehealth interventions provided by a multidisciplinary team to integrate combined telecommunication modalities for patients with SCI. The findings of this scoping review may inform policymakers, healthcare professionals, and local/national stakeholders engaged in the planning, implementation, and delivery of virtual services for the SCI population.

*Keywords:* telehealth; Spinal Cord Injury (SCI); telerehabilitation; telemedicine; virtual care; models of telehealth services; virtual delivery of healthcare; community-dwelling Adults with Spinal Cord Injury (SCI); Scoping Review

## **2.1 INTRODUCTION**

### **2.1.1 Background**

In Canada, approximately 86,000 people live with spinal cord injury (SCI), with an additional 3675 new cases each year.<sup>1</sup> Spinal Cord Injury leads to a full or partial loss of sensory, motor, and/or autonomic function that can be severe and often life-threatening.<sup>2</sup> SCI is commonly classified by distinct characteristics of the injury such as the mechanism of injury (traumatic or non-traumatic), type of injury (complete vs. incomplete), level of neurological spinal injury (cervical, thoracic, lumbar, and sacral-level injuries), and the severity of injury widely rated by American Spinal Injury Association Impairment Scale (AIS).<sup>3</sup>

SCI may result in severe chronic morbidity from secondary complications that can be chronic in nature,<sup>4</sup> and include respiratory concerns, urinary and bowel issues, chronic pain, pressure ulcers, psychosocial complications, and bone fracture and osteoporosis.<sup>5</sup> These may lead to decreased functional independence, health-related quality of life, and community participation, as well as increased rates of hospitalization, and loss of employability.<sup>5</sup> Thus, despite the relatively low incidence and prevalence rates of SCI, the associated health conditions contribute to a significant economic impact and financial burden for the patients and their caregivers.<sup>6</sup> In Canada, the net lifetime cost of a person with SCI is estimated to vary between \$1.5-\$3.0 million,<sup>6</sup> and evidence suggests that the direct healthcare cost of people with SCI is eight times that of their non-SCI age-matched peers.<sup>6</sup> Therefore, strategies that focus on prevention, early detection, and management of the sequelae of SCI are critical to improve functional level and quality of life in community-dwelling adults with SCI.<sup>5,7,8</sup> Improved self-management skills, rehabilitation, and access to proactive multidisciplinary healthcare teams are needed to reduce the morbidity and mortality rates associated with chronic conditions in patients with SCI, as well as alleviating the economic burden.<sup>9,10</sup>

People with SCI may face several barriers in accessing healthcare services, including lack of transportation, physical obstacles, lack of preventative health screenings and primary care physician's expert knowledge regarding secondary complications and preventative care issues related to SCI.<sup>11,12</sup> Research suggests that adequate access to primary healthcare services may reduce the risk of developing long-term secondary complications associated with SCI, as well as chronic illnesses.<sup>11,12</sup> However, a scoping review by McColl *et al*<sup>12</sup> found that despite patients with SCI being significantly dependent on primary care, their various medical needs, especially those related to rehabilitation services, are poorly met.<sup>12</sup>

Telehealth is one strategy that may help to fill unmet care needs among individuals with SCI. Telehealth is defined as the delivery of information and health-related services via telecommunication technologies.<sup>13</sup> Moreover, the present global COVID-19 pandemic has further emphasized the importance of telehealth, facilitating the continuation of primary healthcare services for patients who need supportive care.<sup>14</sup> Telerehabilitation is a growing application of telehealth that involves the virtual delivery of rehabilitation services, including training, education, self-management and compensatory strategies, and monitoring to patients with impairments and disabilities.<sup>14</sup> Literature suggests that several telerehabilitation/telehealth programs exist, particularly for patients with SCI, ensuring continuity of rehabilitation and follow-up after discharge to prevent secondary complications.<sup>11</sup> As telehealth is increasingly used to help with the delivery and follow-up of healthcare services, especially during the present global COVID-19 pandemic, there remains a need to determine the status of telehealth for community-dwelling adults with SCI.

### **2.1.2 Objectives**

With the increasing use of telehealth for delivery and follow-up of healthcare services for patients with SCI, a scoping review was conducted to systematically review and identify the gaps in the literature. The purpose of this scoping review was to identify, describe, and compare models of virtually-delivered rehabilitative interventions and health services in patients with SCI living in the community. The research question guiding this scoping review was: What models of telehealth/telerehabilitation services are available to community-dwelling adults with spinal cord injuries? Through this review, we identified: (1) characteristics (e.g., types of telerehabilitation services provided, format/delivery, intensity/frequency/duration, technology component, underlying framework or theories, etc.) of distinct telehealth intervention and/or services used to prevent, treat, and manage secondary complications of SCI; (2) characteristics of the target population (e.g., age, sex, level of injury, time since injury, related secondary complications, etc.); (3) characteristics of studies conducted (e.g., qualitative, quantitative, mixed-methods, systematic reviews, scoping reviews, etc.), and (4) outcomes examined.

## **2.2 MATERIALS AND METHODS**

This scoping review was performed in accordance with the framework from Arksey & O'Malley<sup>15</sup>. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) was also used to guide the reporting of this scoping review.<sup>16</sup>

### **2.2.1 Inclusion Criteria**

To be included in this review, articles needed to focus on the identification, implementation, and/or evaluation of telehealth/telerehabilitation interventions, including primary healthcare services and self-management services delivered in the community and



home-based settings. This review included articles involving community-dwelling adults with SCI who are 18 years or older. Qualitative, quantitative, mixed-methods studies, and sources of expert opinion, textual and narrative data, and reviews reported in English and published between 1990 to February 1<sup>st</sup>, 2022, were included. Studies were excluded if they met one of the following criteria: (1) abstracts only, conferences and posters, study protocols without the published full-text article, editorial letters, and one-page commentaries; (2) studies conducted in middle or low-income countries as the results of this research were specifically tailored to the Canadian SCI community based on the North American healthcare system; (3) published prior to 1990 as the majority of research on the topic of telehealth and thus the use of telecommunication technologies to aid the delivery and follow-up of healthcare services occurred after this date.

### **2.2.2 Search Strategy and Information Sources**

A comprehensive search strategy was performed by the primary investigator (SM) to include all relevant literature published between 1990 to February 1<sup>st</sup>, 2022, using the following databases: Ovid Medline (1946-Feb 2022, Ovid Embase (1974-Feb 2022), Ovid Psycinfo (1806-Feb 2022), Web of Science, and CINAHL (1985-Feb 2022). Initially, the review was planned to consider the literature for three separate themes: Theme 1: Primary care services delivered virtually to patients with SCI; Theme 2: Telerehabilitation services delivered virtually to patients with SCI, and Theme 3: Self-management interventions delivered virtually to patients with SCI. However, following the consultation with a Medical Librarian in Health Sciences at McMaster University, the authors ran one overarching search using medical subject headings and text words related to virtual care and spinal cord injuries. Investigators reviewed the final search results to ensure all the initial theme-based articles were included. The final search strategy for Ovid Medline can be found in Appendix 2A. A manual search of the reference lists of recent

studies was conducted to ensure the inclusion of all relevant articles in the scoping review.

Previously published systematic, narrative, and scoping reviews of similar topics were reviewed for related results to ensure all relevant references were included in this review.

### **2.2.3 Study Selection**

Eligible articles were identified using a 3-step process. In step 1, one reviewer (SM) collected the search results and then removed the duplicates. In the second step, two reviewers (S.M. and A.M.) independently reviewed the titles and abstracts of the identified articles that appeared to meet the inclusion criteria. In step 3, the same reviewers evaluated full texts of the remaining publications identified by our searches to include potential relevant publications. Covidence software was used to support and synthesize the process of scoping review production.<sup>17</sup> Discrepancies were resolved via discussion between the reviewers. If reviewers failed to reach a consensus, a third expert reviewer (J.R.) was consulted for the final decision about inclusion.

### **2.2.4 Data Extraction**

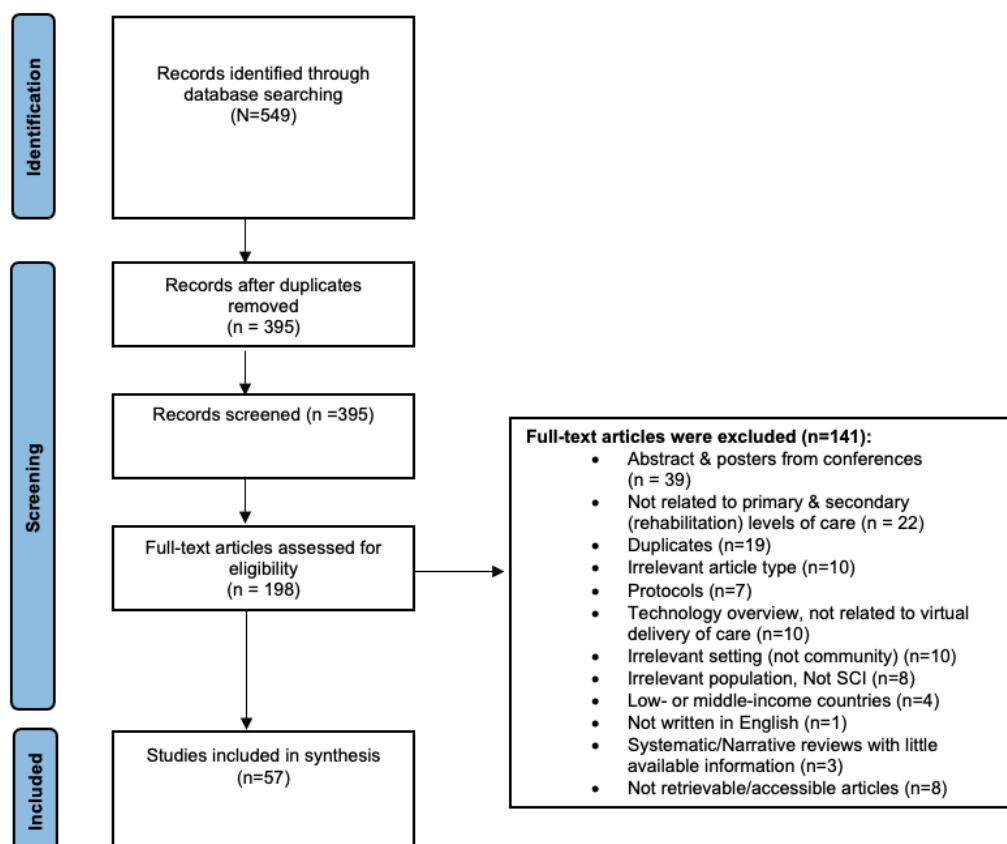
Data from eligible studies were extracted using data extraction forms developed by the research team (refer to Appendix 2B). Two separate data extraction tools were designed for qualitative and quantitative studies. Information extracted from studies included study characteristics (e.g. year of publication, country of study, the purpose of the study, study design), participant characteristics (e.g., age, sex, time since injury, detail of SCI, secondary complications related to SCI), key characteristics of the intervention/programs/ services (e.g. description, the format of delivery, facilitator, duration, frequency, intensity, underlying theories for the intervention, types of intervention, the type of technology modality), outcome measures,

and results. For qualitative studies, themes and findings were collated by the lead reviewer (S.M.).

## 2.3 RESULTS

### 2.3.1 Source of Evidence

Initially, 594 studies were imported into the Covidence software. After duplicates were removed, 395 citations were retained from searches of electronic databases and article references. After title and abstract screening, 198 articles were included for the full-text review process. Of these 198 articles, 141 were excluded (see figure 1 for reasons) and 57 studies met the inclusion criteria. Data extraction was completed for the remaining 57 studies, which were considered eligible for this review. The PRISMA flowchart is shown in Figure 1.



**Figure 1.** PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flowchart.

### **2.3.2 Study Characteristics**

A descriptive summary for each experimental and non-experimental study are included in Tables 1 and 2 (please refer to Supplemental Tables 1 & 2), respectively.<sup>8,12,13,14,18-70</sup> The included papers consisted of 12 qualitative studies, 28 quantitative studies conducted in one-on-one format, 3 mixed-method studies, 4 systematic reviews, 2 scoping reviews, 5 conceptual reviews, 2 narrative reviews, and 1 meta-analysis. These studies were conducted in nine countries: United States (n=32), Canada (n=11), Australia (n=6), Italy (n=2), South Korea (n=2), United Kingdom (n=1), Netherlands (n=1), Sweden (n=1), and Norway (n=1).

### **2.3.3 Participant Characteristics**

The mean sample size of the included articles was relatively small, with an average of 57 subjects, but ranged from 1 to 15,028 across quantitative (n=32) and qualitative (n=11) studies that specified sample size. The age of participants ranged from 18 and 85 years.

### **2.3.4 Spinal Cord Injury Type**

Approximately half of the included studies (n=31) reported the injury characteristics of the participants. Two studies indicated the type of the SCI, where participants had both traumatic and non-traumatic injuries.<sup>21,22</sup> Injury levels (i.e., cervical, thoracic, and lumbar spine injuries), neurologic completeness, and paralysis (paraplegia and tetraplegia) varied among the

participants of the included studies, indicating heterogeneous nature of participants under investigation.

### **2.3.5 Outcomes**

#### **Physical Activity/Leisure Time Physical Activity Motivation & Participation**

Fourteen articles focused on improving physical activity (PA) and leisure-time physical activity (LTPA) participation, motivation, and exercise endurance.<sup>18,20,21,23-25,27,36,43,45-47,49,50</sup> There were 11 articles that quantitatively assessed the effectiveness of intervention/services to improve motivation and participation in PA and LTPA (Supplemental Table 1).<sup>18,21-25,27,36,43,45,46</sup> Of the 11 studies, 3 used telephone counselling sessions,<sup>21,24,43</sup> 5 studies applied web-based applications/platforms,<sup>18,23,25,45,46</sup> and the remaining 3 studies used web-based video conferencing software as a means of delivering home-based exercise interventions.<sup>27,36,48</sup> The duration of the interventions ranged between 2 and 6 months. Nine<sup>18,21-25,27,43,45</sup> of the 11 studies described the planned frequency of contact with the provider, ranging from once a week to once a month, while only 1 study did not report the frequency of peer/provider interaction.<sup>46</sup> All 11 studies provided a combination of services aimed at monitoring, providing feedback, motivational and informational support to the target population. Six studies<sup>18,21,27,43,46,47</sup> indicated that an exercise/PA/LTPA counsellor provided the intervention whereas 2 studies<sup>43,46</sup> reported registered kinesiologists who were trained in motivational interviewing techniques, and behavioral change theories, facilitated the service provision. In contrast, 4 studies<sup>23-25,49</sup> reported that an experienced physiotherapist monitored the self-regulatory interventions. Only one study<sup>39</sup> reported that the telehealth coordinator monitored the training of the participants involved in the home-based video-conference program. The outcomes most frequently used for measuring PA

and LTPA were the 7-day Self-report LTPA Questionnaire and World Health Organization Quality of Life BREF Scale (WHO-QOL BREF). In most of the studies (n=10),<sup>18,21-23,25,27,39,43,45,46</sup> the interventions had favorable outcomes elevating the participant's engagement in LTPA and PA levels. In contrast, 1 study indicated no improvement in LTPA/PA levels but decreased depressive symptoms.<sup>24</sup>

### **Chronic Pain**

Two quantitative pre-post studies<sup>32,38</sup> and 1 qualitative study<sup>52</sup> focused on self-management strategies for reducing chronic pain in adults with SCI (see Supplemental Table 1&2). Of the 2 quantitative studies, one used an internet-based chronic pain program, while the other used video-conferencing software to educate participants on self-management skills and exercise training to reduce pain, respectively.<sup>38,32</sup> In both studies, an experienced physiotherapist monitored and contacted participants if needed.<sup>38,32</sup> All studies reported the duration of the intervention which ranged between 8 weeks and 6 months. By contrast, only 2 studies noted the frequency of contact which ranged between 3 times per week to 2 calls per month.<sup>32,52</sup> The 2 quantitative studies reported on the measures used to assess chronic pain, including the Pain Disability Index (PDI)<sup>38</sup>, Pain Self-efficacy Questionnaire (PSEQ)<sup>38</sup>, and the Shoulder Rating Questionnaire (SRQ)<sup>32</sup>, which measures upper extremity function and pain intensity. The two quantitative studies demonstrated reduced pain and improved pain-related disability among adults with SCI.<sup>32,38</sup> One study targeted both chronic pain and psychosocial outcomes resulted in a reduction in pain, and depression, and improved life satisfaction.<sup>38</sup> The qualitative study which explored the peer health coaches' role as a provider, highlighted the important role of peer health coaches in promoting chronic pain self-management strategies among peers with SCI.<sup>52</sup>

### **Pressure Ulcers/Sores/Injuries, & Skin/Wound Care**

Overall, 10 articles specifically focused on prevention, treatment, or self-management of pressure ulcers and wound care (see Supplemental Table 1&2).<sup>30,34,37,53-59</sup> Out of the 10 articles, 4 studies used a video-phone (Picasso at&t) modality to transmit still images and audio over a standard telephone line and to hold audio-video consultation sessions with the SCI population.<sup>30,37,53,54</sup> All 4 studies provided monitoring, wound/pressure ulcers management services and informational support. The frequency of contact with providers varied, with an average of 7 visits per month. The duration of interventions varied from 6 weeks to 12 weeks. The only outcome measure used to assess pressure ulcers was the Pressure Ulcer Scale for Healing tool v. 3.0 (PUSH).<sup>53</sup> All the interventions demonstrated favorable results in successfully managing pressure injuries and wounds via telehealth. Two systematic reviews<sup>55,56</sup> and 1 scoping review<sup>57</sup> identified evidence to inform the development of telehealth techniques used to prevent, treat, and self-manage pressure ulcers in patients with SCI following discharge. One qualitative study that used semi-structured interviews<sup>34</sup> and 1 modelled analysis<sup>58</sup> reported on patients' experience using a mobile educational app for pressure ulcer prevention and evaluated costs and savings associated with telehealth services for preventing and treating pressure ulcers, respectively. The results of the modelled analysis found that telehealth services were less expensive than standard care when low-cost technology was used but more expensive in cases where high-cost interactive devices were applied in patients' home settings<sup>58</sup>.

### **Psychosocial Function**

Eight articles focused on the effects of telehealth services in reducing psychosocial problems such as depression, anxiety, life satisfaction, community participation and reintegration (see Supplemental Table 1&2) <sup>13,28,40,41,51,60-62</sup>. Telehealth modalities and delivery methods included telephone counselling via simple telephone lines,<sup>13,28,61,62</sup> video-based counselling

sessions using personal computers,<sup>13</sup> and web-based programs on any devices accessing internet networks.<sup>40,41,51</sup> In 2 studies involving telephone and video counselling sessions, interventions were provided by a trained nurse and peers who have lived experience with SCI trained in motivational interviewing techniques.<sup>13,28</sup> In 2 studies, patients used the web-based interventions independently without facilitator involvement or supervision.<sup>40,41</sup> The most frequent measures used to assess psychosocial functioning were Depression, Anxiety and Stress Scale–Short Form,<sup>40,41</sup> the Quality of Well-Being Scale,<sup>13,41</sup> Craig Handicap Assessment and Reporting Technique Short Form10 assessing community participation,<sup>26,29,41,42</sup> and Patient Health Questionnaire-9 measuring depression severity.<sup>28</sup> The results from the 4 studies were inconsistent in the effects of psychosocial treatments on depressive symptoms, life satisfaction, and quality of life. Two studies demonstrated improvement in depressive symptoms such as improved sleep and psychomotor symptoms, positive appetite changes, and increased energy<sup>40,41</sup> whereas 2 showed no improvement in the psychosocial and health-related quality of life outcomes.<sup>13,28</sup> Two qualitative studies reported on models of service delivery supporting community reintegration and efficiency of psychological interventions delivered by telephone on emotional outcomes.<sup>51,60</sup> One meta-analysis and 1 systematic review evaluated the impact of virtually-delivered psychological interventions on the psychological functioning of adults with SCI.<sup>61,62</sup> The systematic review<sup>62</sup> results indicated tele-counselling enhanced management of common comorbidities following SCI, including pain and sleep difficulties. The meta-analysis<sup>61</sup> results demonstrated significant enhancement in coping skills and strategies, depression, and community reintegration following SCI. Ten studies used a cognitive behavior change theory and psychological principle in addressing cognitive behavioral aspects of psychosocial conditions following SCI.<sup>20,21,26,38,40,41,43,46,50,51</sup>



## **Addressing Multiple Secondary Complications**

Thirteen studies focused on multiple secondary complications, including pressure ulcers/wound care, urinary tract infections, a range of psychosocial problems, and community participation, instead of addressing a single complication (see Supplemental Table 1&2).<sup>7,11,26,29,31,39,42,44,48,63-66</sup> From the 7 studies<sup>7,26,29,31,39,42,44</sup> which evaluated interventions for multiple secondary complications, telehealth delivery included video-conferencing platforms (n=1),<sup>44</sup> virtual web-based/mobile applications (n=3),<sup>31,39,42</sup> telephone (n=1),<sup>29</sup> and automated calls using interactive voice response system (n=2).<sup>7,26</sup> The duration of the interventions ranged from 4 months to 9 months. Only 3 studies reported the frequency of interventions ranging from once a week and biweekly interactions.<sup>29,31,44</sup> The multi-component interventions were either provided by registered nurses (n=1), physiotherapists (n=2), occupational therapists (n=1), SCI specialists (n=1), and primary care physicians (n=1). Study results varied from no improvement to significant positive outcomes. Narrative reviews (n=2),<sup>63,65</sup> a systematic review (n=1),<sup>66</sup> conceptual review (n=1),<sup>64</sup> and qualitative studies (n=2)<sup>11,48</sup> reported the use of telehealth for patients with SCI who had multiple secondary complications. The patient/provider's perspective about the potential effects of telehealth services regarding the occurrence of secondary complications as well as higher levels of engagement with peer support components respectively were described in the qualitative studies.<sup>11,48</sup>

## **Oral Health**

Two quantitative studies reported participants' satisfaction, adaptability of and user friendliness of home oral care telecare programs, leading to improved oral and gingival health in patients with SCI.<sup>33,35</sup> Three qualitative studies reported factors enabling the implementation of

telehealth services to address oral care and described ways to integrate tele-oral care services into routine clinical practice.<sup>19,67,68</sup>

### **Increased Use of Telehealth in COVID Era**

Two conceptual reviews<sup>14,69</sup> discussed how, in the time of COVID-19, telerehabilitation services maintained patient-provider interaction and access to essential healthcare services. These services may otherwise have been interrupted by physical isolation and social distancing regulations in place during the global pandemic.<sup>14,69</sup>

### **Telehealth Use in Veterans with SCI**

One cross-sectional descriptive study<sup>22</sup> and 1 literature review<sup>70</sup> investigated the models of telehealth use provided by United States Army Veterans programs, particularly veterans with SCI. These 2 studies mainly discussed the important role of leadership support merged with telehealth technologies allowing for follow-up of long-term self-management of patients with SCI.<sup>22,70</sup>

## **2.4 DISCUSSION**

### **2.4.1 Principal Findings**

This scoping review mapped literature about the telehealth services provided to community-dwelling adults with SCI. In this review, the extracted results are classified under the main categories for which services were delivered. These included physical activity/LTPA motivation and participation, chronic pain, pressure ulcers/sores and skin/wound care, psychosocial dysfunctioning, and oral health. The results of this paper also highlighted the importance of telerehabilitation services in the time of COVID-19 to increase access to healthcare services for community-dwelling adults with SCI.

There was inconsistency in reporting the demographic characteristics of participants, especially the level and type of the injury. Most of the studies included more male participants than women. There was an upward trend in the number of publications since 2015. This upward trend may reflect an increase in the need for telehealth interventions, together with the availability, acceptability, and increased competency with telehealth technologies by healthcare professionals and patients with chronic neurologic conditions, particularly community-dwelling adults with SCI.<sup>2-5,7-9,11,14,18-20,22-25,27-29,31,34,36,38,39,41-47,49-52,55,57,60,63,65,68,70</sup> Recent studies conducted during the COVID-19 pandemic support the need for telerehabilitation and telehealth for patients with neurological deficits such as SCI.<sup>14,69</sup> The most recent research indicates that community-dwelling adults with chronic conditions are becoming more engaged with using cost-efficient, easy-to-use technologies in accessing essential healthcare services, especially during the current pandemic.<sup>14,69</sup> For example, telehealth has been used to provide indirect contact between the psychiatrists and patients, enhancing access to psychological wellness, which may be interrupted due to pandemic-related physical and social isolation.<sup>14</sup>

A number of articles in this review evaluated the effectiveness, implementation, and use of existing telehealth services to address secondary complications. Various formats and means of virtual service delivery were used such as web-based platforms and applications, video conferencing software, telephone counselling sessions and automated calls using simple telephone lines. Patients reported greater satisfaction with video-based service delivery rather than telephone communication, resulting in more intervention engagements and positive clinical outcomes.<sup>29</sup> Results from this review suggest that the application of virtual, live, peer or coach support is more engaging to promote health behaviors and outcomes among adults with chronic neurologic conditions. This review reported enhanced skin integrity among the community-

dwelling adults with SCI who used live video-based platforms to promote skincare behavior.<sup>29</sup>

There was inconsistency in reporting the duration of interventions and frequency of contact with the providers.

The findings of this review suggest that most telehealth interventions and services carried out in the home and community were combined with at least one behavioral technique and training.<sup>20,21,26,38,40,41,43,46,50,51</sup> Behavioral training incorporated into the interventions included goal setting, identification of barriers, problem-solving, feedback about performance, emotional support, and decision making, which primarily resulted in the development of self-management skills, and reduction or control of the secondary conditions. These findings confirm the findings from the conceptual review conducted by Dobkin (2016) that telerehabilitation technologies offer ways to remotely include behavioral training to self-coordinate (self-navigate /self-manage) their primary care services resulting in reduced impairment and disability after SCI.<sup>50</sup>

The qualitative studies and reviews included in this scoping review indicate that leadership support and acceptability by management in healthcare facilities influence the implementation and maintenance of telerehabilitation use in routine practice. This finding is consistent with a study conducted by Moehr et al., which reported that continuous coordination and guidance by management teams lead to successful incorporation of telerehabilitation in clinical routine<sup>71</sup>.

Finally, qualitative studies reported high acceptability and satisfaction with telehealth services in patients with SCI, mainly attributed to the accessibility, convenience, and interpersonal interaction with telecare coaches and providers who have expert knowledge in preventing and treating secondary complications following SCI. Telehealth services are reported to address the barrier of limited local expert knowledge to meet the medical needs of patients

with SCI who live in their communities.<sup>12</sup> In addition, patients with SCI appreciated the ability to have face-to-face virtual interaction with their healthcare providers, especially highlighted the importance of designing peer-led interventions (e.g., My CareMy Call peer-led interventions) and peer mentors' powerful role in promoting self-management strategies to prevent secondary complications in adults with SCI. Furthermore, peer mentors are widely accepted as a source of social support while fulfilling the roles of role model, advisor, and supporter by promoting self-management skills through educating, strategizing, and more importantly emotionally connecting and building trust with adults with SCI.<sup>52</sup> On the other hand, as discussed by Yuen et al., one of the main issues in the performance and application of telehealth services for patients with SCI is the lack of high-speed internet services and the incompatibility of individuals' computers with videoconferencing applications.<sup>35</sup>

The findings of our scoping review indicate that telehealth technologies are potentially effective strategies for addressing disparities in providing quality care and managing multiple health concerns in patients with SCI. The results highlighted the need for future research in the following areas: (1) increased involvement of multidisciplinary teams to facilitate interventions for managing secondary complications as there were no intervention-based studies reported using multidisciplinary team approaches; (2) implementation of underlying theory or model to inform telehealth services supporting the intended outcomes of the intervention, as majority of the included studies lacked underlying theories or frameworks; (3) present more consistent details about population characteristics, mainly related to SCI; and (4) address gender differences in user needs and engagement with SCI.

#### **2.4.2 Limitations**

Many of the studies were conducted in the United States and Canada, where healthcare systems vary from other countries, limiting the generalizability of the results to more North American context. This review also only included studies conducted in high income countries and thus does not reflect telehealth delivery models for patients with SCI in low-income countries. This review was limited to English written articles. Therefore, it is possible there may be missing studies available in other languages. Accordingly, a systematic review is needed to obtain a more accurate view on the effectiveness of telehealth models of service delivery in community-dwelling adults with SCI.

## **2.5 CONCLUSION**

This scoping review mapped the existing literature on what is known about the telehealth services provided to community-dwelling adults with SCI. Multiple gaps were revealed, highlighting the need for future research in the following areas. Combined findings from this scoping review and the qualitative study exploring the perspective of key stakeholders with about telehealth services delivered to community-dwelling adults with SCI will be used to inform the policymakers, healthcare professionals, and local/national stakeholders who are engaged in the planning, implementation, and funding process of establishing a virtual clinic for the SCI population.

## **2.6 ACKNOWLEDGEMENTS**

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## **2.7 CONFLICTS OF INTEREST**

None declared.

## 2.8 Reference

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## Appendix 2A. Ovid Medline Search Strategy

### Final Search Strategy for Ovid Medline

OVID Medline Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R)

Daily and Ovid MEDLINE(R) 1946 to Present

Search Strategy:

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1	exp Telemedicine/	40974	
2	telemedicine.mp.	43448	
3	virtual care.mp.	813	
4	mobile health.mp.	10747	
5	telehealth.mp.	10778	
6	tele-health.mp.	248	
7	eHealth.mp.	5945	
8	mHealth.mp.	7727	
9	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8	65369	
10	exp Spinal Cord Injuries/	53735	
11	spinal cord injuries.mp	44348	
12	spinal cord contusion.mp.	733	
13	spinal cord contusions.mp.	32	
14	spinal cord injury.mp.	40269	
15	spinal cord laceration.mp.	3	
16	spinal cord transection*.mp.	1535	
17	spinal cord trauma*.mp.	975	
18	exp Paraplegia/	13393	
19	exp Quadriplegia/	8343	
20	paraplegia.mp.	21701	
21	quadriplegia.mp.	10037	
22	10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21	89622	
23	9 and 22	174	

**Appendix 2B. Data Extraction Forms****Appendix 2.1B. Data Extraction Form for Quantitative Studies**

Reviewer's Initials:		Date:
First author's last name:		Year:
<b>Eligibility:</b>		
<input type="checkbox"/> PT or <input type="checkbox"/> OT or <input type="checkbox"/> Both <input type="checkbox"/> Age $\geq 18$ yrs. <input type="checkbox"/> High or middle income country (Specify):		<input type="checkbox"/> English language <input type="checkbox"/> Community-Based persons with SCI <input type="checkbox"/> Model of service provision or intervention <input type="checkbox"/> Virtual delivery of interventions
<b>Article type:</b>		
<input type="checkbox"/> Non-experimental design	<input type="checkbox"/> Experimental design	
<input type="checkbox"/> Qualitative study <input type="checkbox"/> Editorial <input type="checkbox"/> Practice guideline <input type="checkbox"/> Review <input type="checkbox"/> Other:	Interventional study <input type="checkbox"/> Pre-post <input type="checkbox"/> Non-randomized trial <input type="checkbox"/> RCT <input type="checkbox"/> Other:	Observational study <input type="checkbox"/> Cross sectional <input type="checkbox"/> Cohort <input type="checkbox"/> Other:
<b>Participant characteristics:</b>		
Total no. of participants		
Age		
Sex	<input type="checkbox"/> male <input type="checkbox"/> female	
Marital status	<input type="checkbox"/> Single <input type="checkbox"/> Married/Common-Law <input type="checkbox"/> Divorced/Separated <input type="checkbox"/> Widowed	
living arrangements	lives <input type="checkbox"/> alone <input type="checkbox"/> with family <input type="checkbox"/> with friends <input type="checkbox"/> other:	
income status	<input type="checkbox"/> low-income <input type="checkbox"/> middle-income <input type="checkbox"/> high-income	
education level	<input type="checkbox"/> grade school <input type="checkbox"/> high school <input type="checkbox"/> college <input type="checkbox"/> university <input type="checkbox"/> graduate school	
working/studying status	<input type="checkbox"/> student full-time <input type="checkbox"/> student part-time <input type="checkbox"/> working full-time <input type="checkbox"/> working part-time <input type="checkbox"/> unemployed <input type="checkbox"/> retired	
time since injury	<input type="checkbox"/> <1 year <input type="checkbox"/> 1-2 years <input type="checkbox"/> 3-5 years <input type="checkbox"/> 6-10 years <input type="checkbox"/> >10 years	

details of SCI	<input type="checkbox"/> traumatic <input type="checkbox"/> Non-traumatic <input type="checkbox"/> Tetraplegia <input type="checkbox"/> Paraplegia <input type="checkbox"/> Incomplete <input type="checkbox"/> Complete	
Mobility	<input type="checkbox"/> Power wheelchair <input type="checkbox"/> Manual wheelchair <input type="checkbox"/> Ambulatory with _____ (aid)	
Comorbidities with SCI	<input type="checkbox"/> Arthritis <input type="checkbox"/> Hypertension <input type="checkbox"/> Heart disease <input type="checkbox"/> Stroke <input type="checkbox"/> Diabetes <input type="checkbox"/> COPD <input type="checkbox"/> Cancer <input type="checkbox"/> Mental illness <input type="checkbox"/> Other (specify):	
Secondary complications related to SCI	<input type="checkbox"/> Pressure sores <input type="checkbox"/> Muscle spasms <input type="checkbox"/> Bladder/bowel dysfunction <input type="checkbox"/> Urinary infection <input type="checkbox"/> Chronic pain <input type="checkbox"/> Sexual dysfunction <input type="checkbox"/> Joint and muscle pain <input type="checkbox"/> range of psychological problems <input type="checkbox"/> Other is (specify):	
<b>Article details:</b>		
Population: <input checked="" type="checkbox"/> Spinal Cord Injury Population		
Setting <input type="checkbox"/> Community (Specify): <input type="checkbox"/> Transitional care		
<b>Research Question/Purpose:</b>		
<b>The paper describes an <input type="checkbox"/> Intervention or <input type="checkbox"/> Model of service delivery</b>		
Theoretical Framework or Model Yes <input type="checkbox"/> No <input type="checkbox"/> Details:		
<b>Intervention details:</b>		
<input type="checkbox"/> Chronic disease management/self-management <input type="checkbox"/> Exercise program/prescription <input type="checkbox"/> Pain management/self-management <input type="checkbox"/> Mobility aid/equipment prescription <input type="checkbox"/> Return to work <input type="checkbox"/> Other: <input type="checkbox"/> ADL training		
Format/Delivery	Delivered by	Intensity, frequency, duration
<input type="checkbox"/> Virtual web-based, individual		

<input type="checkbox"/> Virtual web-based, group <input type="checkbox"/> Virtual app, individual <input type="checkbox"/> Virtual app, group <input type="checkbox"/> Telephone <input type="checkbox"/> Other:		
-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	--	--

<b>Additional details about the intervention</b>			
<b>Model of Service Delivery details:</b>			
<b>Describes the role of the OT/PT <input type="checkbox"/> Yes <input type="checkbox"/> No      Please provide details.</b>			
<b>Describes OT/PT needs for the spinal cord injury population ? <input type="checkbox"/> Yes <input type="checkbox"/> No</b>			
<input type="checkbox"/> Physical health problem <input type="checkbox"/> Mental health problem <input type="checkbox"/> Navigating community resources/programs <input type="checkbox"/> General health/lifestyle issue		<input type="checkbox"/> Referral to other health care providers <input type="checkbox"/> Referral to other sectors (Social services) <input type="checkbox"/> Other:	
<b>Describes facilitators and barriers to service delivery in spinal cord injury populations? <input type="checkbox"/> Yes <input type="checkbox"/> No</b>			
<b>Barriers:</b>		<b>Facilitators:</b>	
<b>Describes health outcomes used in spinal cord injury populations? <input type="checkbox"/> Yes <input type="checkbox"/> No      Please list.</b>			
<b>For experimental studies only</b>			
Sample Size	Total	Int:	Control:
Groups' mean age		Int:	Control:

Sex	Int:	%F	%M	%Other	Control:	%F	%M	%Other
Results:								
Study limitations								

### Appendix 2.2B. Data Extraction Form for Qualitative or Mixed Methods Studies

Reviewer's Name:		Date:
First author's last name:		Year:
Type of study	<input type="checkbox"/> Qualitative <input type="checkbox"/> Mixed Methods <input type="checkbox"/> Editorial <input type="checkbox"/> Practice guideline <input type="checkbox"/> Review <input type="checkbox"/> Other:	
Research approach	<input type="checkbox"/> Phenomenology <input type="checkbox"/> Ethnography <input type="checkbox"/> Grounded Theory <input type="checkbox"/> Other	

Article details
Population: <input checked="" type="checkbox"/> Spinal Cord Injury Population

Participant Characteristics	
Total no. of participants	
Age	
Sex	<input type="checkbox"/> male <input type="checkbox"/> female
Marital status	<input type="checkbox"/> Single <input type="checkbox"/> Married/Common-Law <input type="checkbox"/> Divorced/Separated <input type="checkbox"/> Widowed
living arrangements	lives <input type="checkbox"/> alone <input type="checkbox"/> with family <input type="checkbox"/> with friends <input type="checkbox"/> other:
income status	<input type="checkbox"/> low-income <input type="checkbox"/> middle-income <input type="checkbox"/> high-income
education level	<input type="checkbox"/> grade school <input type="checkbox"/> high school <input type="checkbox"/> college <input type="checkbox"/> university <input type="checkbox"/> graduate school
working/studying status	<input type="checkbox"/> student full-time <input type="checkbox"/> student part-time <input type="checkbox"/> working full-time <input type="checkbox"/> working part-time <input type="checkbox"/> unemployed <input type="checkbox"/> retired
time since injury	<input type="checkbox"/> <1 year <input type="checkbox"/> 1-2 years <input type="checkbox"/> 3-5 years <input type="checkbox"/> 6-10 years <input type="checkbox"/> >10 years
details of SCI	<input type="checkbox"/> traumatic <input type="checkbox"/> non-traumatic <input type="checkbox"/> Tetraplegia <input type="checkbox"/> Complete <input type="checkbox"/> Paraplegia <input type="checkbox"/> Incomplete



Mobility	<input type="checkbox"/> Power wheelchair <input type="checkbox"/> Ambulatory with _____ (aid) <input type="checkbox"/> Manual wheelchair
Comorbidities with SCI	<input type="checkbox"/> Arthritis <input type="checkbox"/> Hypertension <input type="checkbox"/> Heart disease <input type="checkbox"/> Stroke <input type="checkbox"/> Diabetes <input type="checkbox"/> COPD <input type="checkbox"/> Cancer <input type="checkbox"/> Mental illness <input type="checkbox"/> Other (specify):
Secondary complications related to SCI	<input type="checkbox"/> Pressure sores <input type="checkbox"/> Muscle spasms <input type="checkbox"/> Bladder/bowel dysfunction <input type="checkbox"/> Urinary infection <input type="checkbox"/> Chronic pain <input type="checkbox"/> Joint and muscle pain <input type="checkbox"/> range of psychological problems <input type="checkbox"/> Sexual dysfunction <input type="checkbox"/> Other is (specify):

### Methods & Results

Study purpose		
Design	<input type="checkbox"/> Interviews	<input type="checkbox"/> Observations
	<input type="checkbox"/> Questionnaires	<input type="checkbox"/> Focus groups
	<input type="checkbox"/> Surveys	<input type="checkbox"/> Other:
Setting		
Duration of participation		
Main Findings/Results		
Conclusions		
limitations & future directions		
Ethical approval obtained for study	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unclear	Withdrawals from study:

### Supplemental Table 1

Please use this link to access the Online Table 1 Excel worksheet: [https://mcmasteru365-my.sharepoint.com/:x:/g/personal/mirbahas\\_mcmaster\\_ca/ETq7Wx9aMZFGgil4UPyhBuoB8znqsC2fjA3dYcwB6pZxvQ?e=v5Ioex](https://mcmasteru365-my.sharepoint.com/:x:/g/personal/mirbahas_mcmaster_ca/ETq7Wx9aMZFGgil4UPyhBuoB8znqsC2fjA3dYcwB6pZxvQ?e=v5Ioex)

### Supplemental Table 2

Please use this link to access the Online Table 2 Excel worksheet: [https://mcmasteru365-my.sharepoint.com/:x:/g/personal/mirbahas\\_mcmaster\\_ca/EZ0ZxluSOwROvmw2YkHXDWABTe9aHQ0JGukhn0ekcxdIiw?e=lGzN7N](https://mcmasteru365-my.sharepoint.com/:x:/g/personal/mirbahas_mcmaster_ca/EZ0ZxluSOwROvmw2YkHXDWABTe9aHQ0JGukhn0ekcxdIiw?e=lGzN7N)

**\*\*Please copy & paste the URL link into your browser for view.\*\***

**CHAPTER THREE:**

**STAKEHOLDER'S PERSPECTIVE ON THE DEVELOPMENT OF A  
VIRTUAL CLINIC FOR PATIENTS WITH SCI: A QUALITATIVE STUDY**

*\*This study has been submitted to the journal of Disability and Rehabilitation: Assistive Technology.*

Shaghayegh Mirbaha<sup>1</sup>, Julie Richardson<sup>1</sup>, Ada Tang<sup>1</sup>, Jenna Smith-Turchyn<sup>1</sup>

*<sup>1</sup>School of Rehabilitation Sciences, McMaster University, Institute of Applied Health Sciences,  
1400 Main Street West, Hamilton, Ontario, Canada*

Corresponding Author: Dr. Jenna Smith-Turchyn

School of Rehabilitation Sciences

McMaster University

1400 Main Street West, Hamilton

Ontario, Canada, L8S 1C7

smithjtf@mcmaster.ca

### 3.0 ABSTRACT

*Purpose:* This study aims to explore the priorities, preferences, and feedback of multiple healthcare professionals to inform the future development of virtual clinics for community-dwelling adults with SCI in Ontario, Canada.

*Methods:* Interpretive description methodology was used to guide our exploration. Semi-structured interviews were conducted with 15 expert healthcare professionals involved in the care of patients with SCI. Interviews were recorded and transcribed verbatim. Interview transcripts were then analyzed using a six-phase thematic analysis approach.

*Results:* HCPs perceived virtual care to improve access to care over the long term, particularly to those living in rural areas, as well as increase connections between different providers. However, participants highlighted that in-person care is still required for management of severe SCI-related sequelae that can be life-threatening, such as pressure ulcers, spasticity, respiratory issues, and bowel and bladder complications.

*Conclusion:* Our findings can be used to inform policymakers, HCPs, and stakeholders involved with SCI rehabilitation when establishing a virtual clinic for patients with SCI. Results of this study found that policymakers and HCPs should consider hybridised (blend of virtual and in-person) healthcare and uptake of multidisciplinary approaches within the virtual healthcare systems.

**Keywords:** Spinal cord injury; rehabilitation; teleSCI; telehealth; healthcare; virtual care; pandemic; Canada

### 3.1 INTRODUCTION

In Canada, approximately 86,000 people sustain SCI, and there are an additional 3675 new cases each year of either traumatic or non-traumatic etiology.<sup>1</sup> SCI leads to a full or partial loss of sensory, motor, and/or autonomic function, which negatively affects an individual's capability to perform activities of daily living, functional independence, and quality of life.<sup>1-3</sup> Despite low incidence rates, SCI is a complicated disorder that leads to considerable morbidity and cost burden on the health system, mainly due to the wide range of secondary health sequelae that frequently occur following SCI.<sup>1</sup> The most common secondary long-term sequelae after SCI include cardiovascular, respiratory issues, bowel and bladder spasticity, pressure ulcers, pain syndrome, psychological, and osteoporosis and bone issues.<sup>3-5</sup> After inpatient rehabilitation, most persons with SCI return to community living, accessing follow-up care from their primary care provider. Where available and accessible, persons with SCI may receive outpatient rehabilitation services and specialty care from providers with expertise in SCI care, such as physiatry, neurology, neuro-psychiatry, sexologist, and physical and occupational therapy.<sup>1</sup> However, there is a lack of adequate community care services for persons with SCI in the long term who live in the community,<sup>6</sup> and evidence suggests that individuals living with SCI are less likely to receive the same level of essential primary care services compared to persons without SCI.<sup>6,7</sup> Limited community care services, such as home-based nursing often lead to secondary sequelae which are preventable with adequate management<sup>6,8-10</sup>. Many of these secondary health issues experienced could be enhanced with improved access to care at the community level and primary care services<sup>6</sup>. Evidence suggests that even when services may be available, community-dwelling adults with SCI face challenges in accessing care, due to geographical distances, lack of transportation, and financial resources<sup>9,11</sup>. Accessibility to community services for SCI have been further limited during the COVID-19 pandemic. Thus, optimal solutions and strategies are

needed to alleviate barriers to rehabilitation services for community-dwelling adults with SCI<sup>1</sup>.

One potential solution for alleviating barriers to access care is the application of telehealth services. *Telehealth* is defined as delivering information and services via telecommunication technologies over distance.<sup>12</sup> In 2016, an international team of leaders in telehealth and SCI met at the International Spinal Cord Society (ISCoS), originating the term “telespinalcordinjury”, or teleSCI<sup>13,14</sup>. Previous research has demonstrated that teleSCI services can improve accessibility to healthcare services and improve self-management of secondary sequelae by reducing travel time and providing convenient, cost-effective services to patients with SCI<sup>13</sup>. However, the acceptance and implementation of the teleSCI were delayed due to structural and socio-cultural barriers such as outdated technological facilities and poor patients and clinician acceptability.<sup>13,15</sup>

### **3.1.1 Purpose & Research Question**

Despite the literature exploring the effectiveness, satisfaction, and adaptability of telehealth services among patients with SCI,<sup>2,9,15,16</sup> there has been little research conducted to date to study the priorities, preferences, and feedback of multiple stakeholder groups to inform the future of virtual clinics, particularly for individuals with SCI. A recent study explored experiences and perceptions of individuals with SCI towards teleSCI services during the COVID-19 global pandemic in British Columbia, Canada.<sup>13</sup> This review of the literature indicated a lack of qualitative studies exploring perspectives of other groups of stakeholders involved with SCI, such as healthcare professionals in relation to teleSCI services.<sup>13</sup> We conducted this study to further understand the perceptions of multiple stakeholders towards teleSCI. The objective was to identify what healthcare professionals (HCPs) regard as the feasible, essential characteristics and potential functions of a virtual clinic for community-dwelling adults with SCI. We were

interested in learning about various HCPs experiences with teleSCI services, their perceptions of the advantages and disadvantages of using these services, and how these experiences and preferences may inform the future development of a virtual clinic providing care to community-dwelling adults with SCI in Ontario, Canada.

## **3.2 METHODS**

### **3.2.1 Study Design**

Qualitative research examines the subjective aspect of social reality and the connections between people, institutions, and the environment in which they live.<sup>17</sup> The interpretive description approach described by Thorne (2016) was used to guide the methodological decisions for this study.<sup>18</sup> Interpretive description seeks out knowledge needed to answer disciplinary questions and informs and alters practice by elaborating on available empirical evidence<sup>18</sup>. Accordingly, this study intends to build on the current understanding of the barriers community-dwelling adults with SCI face accessing in-person primary care and rehabilitative services by exploring the healthcare professionals' application of teleSCI services. The results of this study have been reported following the Consolidated Criteria for Reporting Qualitative Research (COREQ) (see Appendix 3A for completed checklist).<sup>19</sup>

### **3.2.2 Participant Recruitment**

Following ethical approval from the Hamilton Integrated Research Ethics Board (HiREB #14373) we recruited HCPs who work in spinal cord injury units. This included occupational therapists, physiotherapists, primary care physicians, physiatrists, social workers, administrators (regional service coordinator, community navigator, and implementation and evaluation specialist with SCI), and managers. Recruitment occurred at five sites: Hamilton Health Sciences

Regional Rehabilitation Centre, SCI Ontario in Waterloo Wellington, St. Joseph's Health Care London-Parkwood Institute-SCI Rehabilitation Program, The Centre for Family Medicine (CFFM) mobility Clinic in Kitchener, and Glenrose Rehabilitation Hospital in Edmonton, Alberta. Participants were recruited through purposive and snowball sampling.<sup>20</sup>

A list of persons involved in SCI care was assembled at the above institutions. Persons at these institutions in positions of care received an email invitation from a member of the research team (SM) to determine interest in participating in this project. Interested respondents were then contacted to schedule an interview date. A snowballing process was also used to collect referrals from interviewees, suggesting potential participants from their known others, who were then contacted by one researcher (SM) with an email inviting them to participate in the study. Recruitment occurred between May and August 2022. The sample size for this study was specified based on the necessity of recruiting participants until data saturation was achieved. For our study, saturation was defined as no new concepts in relation to our research question and purposes were generated from the interviews.<sup>21</sup>

### **3.2.3 Data Collection**

Written informed consent was collected from each participant prior to the scheduled interview session, with verbal confirmation of consent conducted at the beginning of the interview sessions (See Appendix 3B). A researcher (SM) conducted individual semi-structured interviews via Zoom video-conferencing platform to conform with physical distancing rules and regulations during COVID-19. The interviewer was not known to the participants prior to the study. During each interview, only the interviewer (SM) and the consenting participant were present. An interview guide was established based on the study's objective and the research question (see Appendix 3C). The established interview guide was pilot tested on the first two

participants, and minor revisions were made before continuing with the remaining interviews. Additional probing questions were applied as needed to ensure participants understood what the interviewer was asking or to extract more information when appropriate. Each interview lasted between 30 to 50 minutes, and all interviews were video-recorded and transcribed verbatim. Prior to conducting the interview, data were collected on each participant's role, current role location, and years of experience with patients with SCI. All identifiable information was cleared from the transcripts for anonymity, with unique study identification numbers assigned to each participant. The transcripts were then checked for accuracy and completeness by the first author (SM).

### **3.2.4 Data Analysis**

Data analysis was performed according to the thematic analysis approach and followed different phases involved in the approach as described by Braun et al.<sup>22</sup> Consistent with interpretive description methodology, the analysis was inductive and began with immersion in the data set by reading and re-reading the transcripts to familiarize oneself fully with the data. Three researchers (SM, JR, JST) independently coded the first four transcripts using a line-by-line coding procedure. These three authors then met to discuss the meaning of codes emerging patterns, reach an agreement, and collate sub-codes into potential major codes and themes following the process of thematic analysis. Following the team discussion and development of a single codebook, the first author (SM) independently coded the remaining transcripts as they were completed. The data was coded using Nvivo 12.0, aggregated into major codes and grouped into themes based on the patterns that emerged. Team members gathered periodically during the analysis to discuss how the developed codes addressed the research question. Differences in



researcher perspectives were resolved through discussion and, if necessary, transcripts were recoded until consensus was achieved. The trustworthiness of our data was achieved by researchers immersing themselves in the collected data by reading and examining it in detail and having multiple team meetings to review the data as described above. Informal analysis was performed concurrently with data collection to determine data saturation. We assured saturation of data was achieved after completion of 15 interviews after which the process of formal analysis began.

### **3.3 RESULTS**

#### **3.3.1 Description of Participants**

A total of 15 HCPs from five sites participated in this study. Four sites were located in three different regions across the province of Ontario, and one site was located in Alberta, Canada. Sites were located in the Hamilton region, London, Waterloo and Wellington, and one site located in Edmonton, Alberta, Canada. Participants included different health professional disciplines as well as healthcare managers/administrators who work in spinal cord injury units (2 occupational therapists, 2 physical therapists, 1 physiatrist, 1 family physician, 1 chiropractor, 1 social worker, 3 program director/manager, 1 SCI implementation & evaluation specialist, 1 education facilitator, and 2 community navigator/regional service coordinator (see Table 1 for participants characteristics). HCPs had between 3- and 25-years of experience working with patients with SCI. All participants mentioned that they were employed in their current role during the Covid-19 pandemic and had some experience with using teleSCI (data provided below).

**Table 1:** characteristics of the participants.

<b>Participant Characteristics (n=15)</b>	
<b>No. (%)</b>	
<b>Health Care professional</b>	
Occupational Therapist (inpatient & outpatient rehab)	2 (13.3)
Physical Therapist (inpatient & outpatient rehab)	2 (13.3)
Physiatrist	1 (6.7)
Program Director/Manager	3 (20.0)
Social Worker	1 (6.7)
Implementation & Evaluation Specialist with SCI	1 (6.7)
Family Physician	1 (6.7)
Chiropractor	1 (6.7)
Education Facilitator	1 (6.7)
Community Navigator / Regional Service Coordinator	2 (13.3)
<b>Sex</b>	
Female	9 (60.0)
Male	6 (40.0)
<b>Location</b>	
The Regional Rehabilitation Center at Hamilton Health Sciences, Ontario	10 (66.7)
SCI Ontario in Waterloo Wellington, Ontario	1 (6.7)
The Center for Family Medicine (CFFM) Mobility Clinic, Kitchener, Ontario	2 (13.3)
Parkwood Institute & St. Joseph's Healthcare, London, Ontario	1 (6.7)
Glenrose Rehabilitation Hospital, Edmonton, Alberta	1 (6.7)

### 3.3.2 Identified Themes, Major Codes, & Sub-Codes

The data from the interviews were coded and grouped into 5 main themes, including: (1) advantages of virtual care; (2) challenges to implementing a virtual clinic; (3) considerations for implementing a virtual clinic for individuals with SCI; (4) pandemic-related experiences; and (5)

calls to action and future directions. Refer to Table 2 for details on the themes, major codes, and sub-codes identified in the study.

**Table 2.** Themes, major codes, and sub-codes.

Major Codes	Sub-Codes
Theme: Advantages to Virtual Care	
Increased access to services	<ul style="list-style-type: none"> <li>Care can continue over a longer period of time</li> <li>Increased geographical reach (i.e., reduced travel time, transportation)</li> </ul>
Increased convenience and connections	<ul style="list-style-type: none"> <li>Convenient to do virtual visits for simple follow-up appointments in terms of ease, comfort, time efficiency, and cost</li> <li>Increased connections between different providers</li> <li>Connection with and education of caregivers for enhanced virtual care provision</li> <li>Increased ability of providers to understand patient's home environment</li> <li>Providing the opportunity for peer support (Development of programs to reconnect patients back with their existing peer groups)</li> </ul>
Theme: Challenges to Implementing a Virtual Clinic	
Potential omissions	<ul style="list-style-type: none"> <li>Lose body language information during virtual visits</li> <li>Inability to perform hands-on examinations with having solely virtual visits</li> </ul>
Technology not accessible	<ul style="list-style-type: none"> <li>Decreased access to technology due to financial constraints</li> <li>Physical inaccessibility to use technology (having the physical capability to turn on/off and navigate through devices)</li> <li>Poor internet access due to geographical location</li> </ul>
Impacting patient-provider relationships	<ul style="list-style-type: none"> <li>Challenges with establishing therapeutic rapport if not seeing patients in-person</li> </ul>
Discomfort with technology	<ul style="list-style-type: none"> <li>Age can be a barrier to technology use</li> <li>Patient or provider acceptance or willingness (reimbursement)</li> </ul>
Theme: Considerations for implementing a virtual clinic for individuals with SCI	
Time after injury continuing care virtually	<ul style="list-style-type: none"> <li>Time starting virtual care depends on each person's level of functioning and healthcare needs</li> <li>Transitional care &amp; community reintegration support</li> </ul>
Modes of technology	<ul style="list-style-type: none"> <li>Video-based versus telephone-based virtual visits</li> <li>modes of technology preference depend on the type of intervention and accessibility of the patients to required technology</li> </ul>
Content of care	<ul style="list-style-type: none"> <li>Different domains of SCI care can be done virtually (i.e., primary care post-rehab services, education, mental health support, assistance with navigation...)</li> <li>Types of care needed to be provided in-person (i.e., physical examinations, hands-on therapies, patients with no caregivers at homes)</li> </ul>

Theme: Pandemic-related Experiences	
COVID-19 pandemic impacts on healthcare access and care provision	<ul style="list-style-type: none"> <li>• Covid-19 pandemic impacts on accessing healthcare services</li> <li>• reduced homecare visits relying on family members as a caregivers</li> <li>• Modes of technology used during the pandemic</li> </ul>
Theme: Calls to Action and Future Directions	
Calls to action and future research directions	<ul style="list-style-type: none"> <li>• Multidisciplinary team approach for SCI management in a virtual setting</li> <li>• Hybrid models of care (providing both options of virtual &amp; in-person visits)</li> </ul>

### Advantages to Virtual Care

HCPs found that increased access to services and increased convenience and connections were primary advantages to virtual care.

#### Increased access to services

The most reported advantage to virtual care was increased geographical reach. All HCPs mentioned the reduction or elimination of travel and associated time and costs to travel to healthcare facilities for in-person standard follow-up appointments that do not require in the patient's physical presence (i.e., transportation, parking, gas) as significant advantages of virtual care for patients with SCI. In particular, HCPs noted that those individuals residing in rural areas benefit more from virtual care.

*“Transportation is a huge issue for many of my clients, because they might need a support person they might have to pay for that transportation, they have to book that, you know, so that can be hugely problematic and if it's not required for what we need to assess, then, to have a virtual option is fantastic”. (Participant P014)*

Another advantage related to the increased access to care commonly mentioned was that care could continue over a longer period of time. Participants believed virtual care would enable the patients and providers to stay connected more efficiently for a longer period. One participant highlighted this, saying,

*"I think advantages are the ability to stay connected longer term providing longer-term support for people when they are reintegrating or have reintegrated into their community". (Participant P011)*

### Increased convenience and connections

The most frequently reported advantage regarding increased connections was virtual care's ability to connect different providers from multiple disciplines. Providers from multiple disciplines raised the issues about the lack of follow-up by different disciplines, general practitioner's knowledge in SCI-related areas, and community access to skilled professionals who are experts in SCI-related issues. Therefore, providers noted the time efficiency associated with virtual care and the ease of connecting different providers from the SCI team together who may reside at a distance.

*"What could be wonderful is the virtual care connection between healthcare providers. So, you have these family doctors who are in the community who really don't have any SCI experience. For these family doctors to be able to virtually connect with an SCI team would be hugely helpful. I think, to be able to access that expertise quickly and easily virtually would be helpful in the Community". (Participant P008)*

Several participants also spoke about the convenience of virtual visits for simple follow-up appointments (i.e., medication follow-up, SCI-related counselling, maintenance and monitoring programs, problem-solving follow-up, and educational-based sessions) that did not require in-person physical assessments.

*"At some point, I think you need to see the patient. But then it would be a lot easier and a lot quicker to have the follow up and ongoing care with virtual care and it is easier for the patient and the practitioner because I find virtual visits are quicker and more time efficient". (Participant P004)*

One of the other frequently noted benefits of virtual care was the opportunity to observe the

surroundings and capture the circumstances of the individual's home environment. HCPs appreciated this opportunity largely for therapy sessions where the therapist could monitor transfers and ambulatory status in patients' home environments, adapting the exercises to fit the patient's particular living environment. One participant stated:

*“That can help us to understand better how they function in real life, not only how they function in my consultation room or my exam room or how they function in a lab... or in the physical therapy gym. Is how actually they're functioning their own lives, being able to connect with them in those environments.... and observe and analyze how they're functioning and help them to improve”. (Participant P006)*

Several participants discussed how teleSCI increased the importance of caregivers' roles for the care of persons with SCI. Several participants reflected that caregivers could assist with setting up the technology devices, in particular for those individuals with limited mobility or hand dysfunction. Many participants also felt that training the caregivers in terms of transfers and routine care would make a significant difference in expanding the range of tasks and assessments accomplished virtually and safely in home environments. More convenient interactions with family members who would not be able to travel and attend the in-person appointment, was indicated by several participants.

*“What we found to be really helpful with virtual care is the role of caregivers. So, the more competent the caregiver is or consistent, use of virtual care gives you [provider] a whole different level of options of what you can ask the person [patient] to do safely. Because you [provider] knew, you had somebody [caregiver] there that had some knowledge and maybe some training in what you [provider] were trying to do with them [patient]”. (Participant P003)*

With respect to the advantages of teleSCI, all HCPs felt the impacts of peer support services for persons with SCI, supporting preparedness for discharge and transition back to the community. HCPs also commented on the critical role that SCI Ontario, Canadian organization that supports research and the quality of life of SCI community, plays in successfully delivering peer support

through virtual services since the start of the Covid-19 pandemic to this patient population. One participant described peer support as:

*“Key component helping people to have successful transitioning” and being “great at helping [patients] navigate [through] some of the barriers that they’re having in the community and help follow-up some of the things that we identified as a concern”.*  
(Participant P001)

### **Challenges to Implementing a Virtual Clinic**

HCPs found that potential omissions, inaccessibility to technology, discomfort with technology, and impacting patient-provider relationships were primary challenges to implementing a virtual clinic.

#### Potential omissions

HCPs consistently raised the issue of the possibility of missing information if solely relying on virtual visits. “...there is something that you need to see someone in-person to assess, you have to put hands on, especially as a therapist” (Participant P008). Additionally, HCPs noted the need for extra caution when providing care virtually as “you cannot read their body language” as well (Participant P015).

#### Inaccessibility to technology

Lack of access to technology was one of the most reported challenges that HCPs perceive as preventing successful virtual care. Several HCPs noted that individuals who reside in rural outreach communities would probably have poor internet connections compared to those living in urban areas. Another concern raised by the participants was the financial constraints that limits

access to technology from an equity and equality point of view. A few participants also suggested the idea of developing programs to supplement devices and the internet for those that cannot afford it.

*“If you don't have internet, you can very quickly, see the utility of that virtual call start to degrade .... then, are you actually seeing the benefit? So, in some cases, I think we just need to think about the financial resources that someone has to have to be able to support the technology side of things”. (Participant P011)*

Many HCPs felt that accessibility is not limited to only owning devices (i.e., iPad, tablet, or computer) or being able to pay for the internet. However, also it can be determined by the physical capability to use and navigate through it. Some HCPs particularly mentioned that the extent to which a person can physically access technology depends on the level of injury (paraplegic vs tetraplegic).

*“There are some people that if they were lower extremity paraplegic, that's really not going to be an issue for them using tablets using laptops etc. For virtual communication...if somebody has upper extremity involvement that definitely can be more challenging”. (Participant P012)*

### Impacting patient-provider relationships

Most HCPs noted that establishing therapeutic rapport and relationship through virtual services was challenging and a potential pitfall of teleSCI. Many participants noted that it is more challenging to build the therapeutic rapport virtually when meeting the patient for the first time, however, easier when there was an existing relationship. However, a few HCPs spoke positively about potential ways to be recognized by providers to establish therapeutic rapport and trust virtually.

*“It's interesting because so many of the patients that we've done virtual care with so far, for the most part, have built up that existing relationship with their health care*



*provider and it's transitioning them from in-person to virtual. So, I think for those [individuals] it's a little bit easier. I think if you're a new patient and you've never seen your healthcare provider in-person, that rapport building takes a little bit longer than it would have before". (Participant P011)*

### Discomfort with technology

HCPs expressed different views about the effects of the age factor on the use, access, and adaptation to virtual care. Many HCPs perceived a broad range of capabilities and proficiencies in using technology among older adults. Some are less comfortable using virtual care and are thought to have less experience with or be less adept at using new technology. In contrast, others may feel more comfortable and experienced using virtual modalities. This finding can be summarized as follows:

*"I feel like it really varies like, not just on age, but age is a huge factor like even myself I'm young 47 but I should tell you like I get messed up on some of the technology, so I have some patients who are in their 70s, who feel very comfortable like using facetime and zoom and they are great. Other people who are like in their 60s 70s 80s and they're never going to have a smartphone". (Participant P005)*

Some participants noted the fact that there may also be a similarly wide range of abilities and proficiencies in utilizing technology, even among younger adults, as one participant stated:

*"There will be a huge gap in terms of age; I have people like seniors who are very good with this [virtual] stuff, and I had some young people who do not like it...right, so it is not like black or white...". (Participant P006)*

Three HCPs described concern on remuneration for time spent on virtual visits. They also expressed their concerns about the removal of the virtual reimbursement policies after the Covid-19 pandemic as the acuity of the pandemic resolves, but expectations for virtual care remain. This can be highlighted as one participant said: *"I have been hearing that they are changing the billing for virtual care, so I see that as a huge thing for the physicians". (Participant P008)*

### **Considerations for Implementing a Virtual Clinic for Individuals with SCI**

Considerations brought forward by participants when implementing a virtual clinic for persons with SCI included time to start a continuum of care virtually following SCI, content of virtual care and modes of technology being used for healthcare delivery.

#### Time to start continuum of care virtually after SCI

The majority of the HCPs noted that the time to start virtual care for patients with SCI mainly depends on the individual's level of their injury, healthcare needs, and level of functioning. These HCPs also perceived that those persons with lower levels of injury, closer to their rehabilitation stages with minor healthcare needs, and higher levels of functioning may better respond to virtual care.

*“I think that the biggest thing is their level of functioning. It depends on what their goals are and what level of functioning they are at. So, if they're more lower functioning and rely on a wheelchair and assistance for a lot of their mobility [then] the virtual system is going to be quite hard for these kind of groups [lower functioning individuals], but if they're higher functioning, like I said I find the system works really well”. (Participant P009)*

HCPs consistently expressed the profound gap for patients with SCI regarding resources and support for community reintegration. These participants also indicated that the optimal time to start virtual care for this patient population is immediately after discharge from inpatient rehabilitation when transitioning back to the community, and so more towards the maintenance and adjustment phases rather than intense inpatient rehabilitation.

*“I think the virtual would probably work well, and that might be better served once they're in an outpatient setting, post discharge from an inpatient so it's not really efficient to do it in inpatient units”. (Participant P013)*

### Content of care

All healthcare professionals believed that monitoring, educational, informational, and counselling-based content could be delivered virtually to accomplish SCI-related rehabilitation goals. Participants also noted that virtual care could be used to provide simple follow-ups, check recommendations' adherence, and to problem solve questions regarding the management of SCI-related routine care (i.e., common bowel and bladder issues, regular skin checks), dietary needs, emotional well-being, and sexual health. One participant discussed how individuals with SCI could receive education for SCI-related secondary preventive actions through virtual encounters, as below:

*“In terms of maintenance phases, they receive a lot of education, while they are inpatient, & while they attend the outpatient. But, once then they're in the community, I'm not sure what level of education [they] might receive... So, educating them for secondary preventive actions will be very effective and efficiently delivered in a virtual format”. (Participant P002)*

However, several HCPs highlighted the importance of in-person visits in cases of more complicated and severe bowel and bladder issues, wound care complications, spasticity, and respiratory concerns. For example, one HCP said,

*“I do think there are some things that are going to require a physical face to face, not with everyone, not with everything, but I do think it is important to sometimes lay hands on certain aspects of what they may be struggling with... whether it's you know urinary issues... wound care, or if they're dealing with spasticity”. (Participant P010)*

A few HCPs commented on the potential of virtual care being introduced to physiotherapy,

particularly for high-functioning (lower-level injury) patients and, in some circumstances, for low-functioning (higher level injury) patients with a trained caregiver. For example,

*“I think it would be nice to have the physio one-on-one consult virtually to really discuss like what are you doing this week, like what are you having trouble with at home? Show me your exercise...why don't you show me yourself doing your exercise? and let me see if I can give you some advice.... So, monitoring the program that they're on and then helping them progress to reach their goals”. (Participant P005)*

Additionally, HCPs spoke to the critical roles that therapeutic recreation therapists, social workers, SCI care coordinators, and community navigators play in assisting patients with SCI with community reintegration, helping individuals access community and financial resources required for home adaptations, or providing occupational advice for the source of income modifications.

### Modes of technology

A few HCPs felt that the preference for a technology mode is “*very situational and very dependent on the individual and their family... depends on sort of who is around that can maybe help them with things*” (Participant P012). Most HCPs generally preferred video-based visits as the primary mode of contact with this patient population, considering using the telephone as the backup plan when video-based visits are not possible. One participant highlighted this, saying:

*“So, the first thing we try is video and then, if that's just not working out for one reason or another, then we go to telephone as the backup and telephone is nearly as good as video. but I think there's more of a connection with the video... as when you communicate by video there's more of a connection with the patient and vice versa”. (Participant P004)*

However, a subset of HCPs preferred phone over video-based visits as they experienced it to be

more convenient and easier for both patient and providers. As one participant explained:

*“Eventually, what ended up happening is that most clinicians just use the phone not even video at all, because it is just so much more convenient. In my primary care practice, [ I see patients] in person 80% [, and] 20% [of visits are] virtual, all of my virtual [visits] are telephone. None of them is video because it is much harder to get the patient to get on to a video... The convenience about the phone thing”. (Participant P007)*

In addition to providers preference mode of technology, a subset of HCPs noted that persons with SCI might prefer phone over video due to varied accessibility issues, including physical inaccessibility, poor internet connectivity, and/or inaccessibility to technology devices. One HCP highlighted this by saying,

*“Some [persons with SCI] prefer phone over video. So, I do think I [provider] personally like video better because, I like to see you and talk to you. But obviously for accessibility some don't have access to video. So, I think you'd need to have both [video & phone]”. (Participant P008)*

## **Pandemic-related Experiences**

### Covid-19 pandemic impacts on accessing healthcare services

All HCPs commented on how the abrupt changes affected inpatient and outpatient services. Most HCPs reported that inpatient rehabilitation services were the least affected by the pandemic, with the largest effect seen in outpatient rehabilitation facilities as they were closed longer than inpatient facilities, shifting from face-to-face to virtual interactions. For instance, two of the participants stated:

*“I had to switch it all to make my outpatient care virtually by phone ...But, for acute care and inpatient rehab, that did not change drastically. The only thing that changed a lot was the visiting policies....”. (Participant P006)*

*“From an outpatient perspective, they were not getting the level of therapy that they needed to support them in their transition from inpatient to community.... People living in the community did not have access to any of their healthcare providers, for the most part, in a face-to-face manner....”*. (Participant P011)

Another program director also commented on how this closure impacted persons’ with SCI access to not only specialized and rehabilitation services but also to primary care services:

*“closures impacted their ability to access, you know specialized outpatient rehab...like all sorts of specialized ambulatory appointments, but also their ability to access their primary care appointments likely”*. (Participant P010)

#### Reduced homecare visits relying on family members as a caregivers

Several HCPs noted that there were limited home care services available to community-dwelling adults with SCI because of the physical distancing protocols during the pandemic lockdown, as one participant elaborated, *“a lot of patients had issues with PSWs [personal support workers] ...PSW workers were sick and could not get into the home to provide care.”* (Participant P008)

HCPs also commented on how family members had to compensate for the lack of home care services, with providers relying on support from them as patients’ caregivers. One participant highlighted this, saying, *“I have some patients, where maybe their spouse does not really provide much care for them... their spouse who is not their caregiver who then had to become caregivers during Covid”*. (Participant P008)

#### Modes of technology used during Covid-19 pandemic

During the first wave of the pandemic, HCPs reported using the available videoconferencing virtual platforms, including Ontario Telemedicine Network (OTN) and VIP4SCI, which were created to connect persons with SCI with their healthcare team and each other. However, HCPs reported being dissatisfied with OTN and VIP4SCI platforms mainly due to their connectivity issues and patients and providers finding the platforms challenging to utilize.

*“As I said, OTN doesn't work. It's just the connectivity is terrible. We all gave up on it... We were all told we had to use it as a starting point, and we were trying, and we literally abandoned all of us in our team because we just couldn't make it work, and the steps for the individual were a lot more than setting up a zoom that has been much more reliable”.* (Participant P015)

The majority of the participants felt that Zoom for healthcare software was easy to use, user-friendly, and more acceptable from both patient and provider viewpoints. One participant highlighted this, stating,

*“In the beginning, we have used the OTN it was a little bit difficult now with zoom I think it's a little bit easier, maybe and it's becoming more accepted more probably more user friendly fairly secure”.* (Participant P002)

## **Calls to Action and Future Directions**

### Hybridized models of care

HCPs, all commented on virtual visits being complementary to in-person appointments. One HCP highlighted this by stating, “you still need some in-person, it would not completely replace in-person, but it would complement [it]” (Participant P014). All HCPs felt positive about continuing with the hybridised healthcare (virtual and in-person), which could create more accessible healthcare for those persons with SCI who reside in remote or rural areas with limited access to healthcare options.

*“We do offer virtual visits if people don't want to come in, in a covid environment or they live in a rural area of fire from here, or they don't have access to certain programs, so we offer that virtual model here”. (Participant P009)*

HCPs commented that they prefer to perform the initial assessment visit with the new patients in person to gather clear history uptake, perform physical examinations, establish rapport, and decide the way in which future visits should be attended (either virtually or in-person).

*“With a patient when they first are referred, they [provider] really need to see the patient face to face for the first time to do sort of a comprehensive physical exam and then make a determination from there of how they want to do the follow ups, virtually or in-person”. (Participant P011)*

One participant also discussed how hybrid care models had been successfully implemented and supported by HCPs in Hamilton Health Sciences outpatient SCI rehabilitation program and some mobility clinics across the province of Ontario.

### Multidisciplinary team approach

All HCPs agreed on the importance of implementing a multidisciplinary approach to optimize care delivery by improving communication between the HCPs and team members involved in caring for patients with SCI. Likewise, virtual care was a perceived benefit in connecting the patient caregivers, including family members and all the healthcare providers, regardless of where they are located. HCPs also reported that using virtual care in establishing multidisciplinary approaches may overcome the issue of limited available community resources by improving the service provision and reducing the travel to specialized centers to receive SCI-related care. One HCP shared that:

*“By multidisciplinary I want to be clear that I'm not only talking about health care teams and traditional healthcare workers, but also talking about family members,*



*community health care workers, homecare people, gym instructors..., and so all of those people who are actually providing services to people with SCI would need to be part of this community". (Participant P006)*

### **3.4 DISCUSSION**

#### **3.4.1 Principal Findings**

This study aimed to identify what HCPs regard as the feasible, essential characteristics and potential functions of a virtual clinic for community-dwelling adults with SCI. We also aimed to learn about various healthcare professionals (HCPs) experiences with teleSCI services, their perceptions of the advantages and disadvantages of using these services, and how these experiences and preferences may impact the future establishment of a virtual clinic for community-dwelling adults with SCI in Ontario, Canada. Stay-at-home orders and lockdown policies during Covid-19 have accelerated the adaption of virtual care in Canada.<sup>23</sup> Provinces across Canada have been looking to virtual care to facilitate safe access to healthcare services, particularly for those with long-term chronic conditions residing in remote locations.<sup>23</sup> Our interpretive analysis contributes to the available understanding of the virtual care properties and features with a unique focus on community-dwelling adults with SCI. Additionally, our discussion points to the thoughtful recommendations noted by different HCPs involved in establishing future virtual clinics for patients with SCI.

Providers in this study consistently spoke to the advantage of virtual care in enhancing access to healthcare services by reducing or eliminating travel time and costs associated with transport to healthcare facilities, especially for those individuals who live in outreach communities in rural locations. A provincial summit was held on November 23, 2016, in

Toronto, Canada, with key stakeholders, including persons with SCI, caregivers, clinicians, and policymakers, supporting this finding of increased geographical reach to generate solutions to current issues related to SCI care.<sup>6</sup> Similarly, this summit concluded that using technology would expand virtual outreach and reduce geographic inequities.<sup>6</sup> Echoing previous research indicating unmet care needs for individuals with SCI, HCPs voiced concerns about the lack of specialists in communities, especially in rural areas.<sup>24,25</sup> This lack of specialty care in rural areas leads to reliance on primary care providers who may lack expertise in SCI care.<sup>24,25</sup> In response to this issue, HCPs viewed virtual care with trained specialists in SCI as a solution for improving access to expertise and longer-term care in the community over distance.

In this study, we identified challenges with virtual care that HCPs perceived based on their experiences. One perceived challenge with virtual care was the possibility of missing information by relying on virtual visits in the absence of in-person visits. HCPs believed virtual visits would not replace the need to conduct hands-on physical examinations in the context of an in-person visit. They noted that in-person visits are central to effective physical examination and essential for establishing therapeutic relationships with new patients who are being seen for the first time with no previously built relationships. A recent qualitative study exploring telehealth challenges during Covid-19 for all types of patient populations, as reported by primary healthcare physicians in Quebec and Massachusetts, also highlights the potential risk of virtual modalities in compromising patient-provider therapeutic relationships and continuity of care.<sup>26</sup> Participants also noted other disadvantages of virtual care, including access issues due to financial constraints, lack of physical functioning to operate technology devices, poor internet connections and lack of infrastructure. This finding is consistent with previous research

indicating increased interest in technological improvements to overcome the physical barriers common in this patient population.<sup>27</sup> HCPs commented on the impact of socioeconomic status and financial constraints limiting virtual use.

HCPs also discussed how age was associated with virtual use. During the Covid-19 pandemic, many of their older patients were experienced and more comfortable in using technology for their health compared to younger patients. However, HCPs expressed that older patients were less likely to utilize video-based visits and likely contributed to higher rates of phone-based visits. Our findings differ from studies exploring telehealth use prior to Covid-19, which reported lower telehealth use with increasing age in other medical specialties.<sup>28</sup> Our findings are supported by a review studying changes in the use of telehealth since the onset of Covid-19, which demonstrated that patients were more likely to use virtual visits with increasing age, suggesting that the Covid-19 pandemic might have changed existing patterns of virtual uptake.<sup>29</sup>

HCPs also consistently raised the issue of the lack of sufficient community resources to mitigate community reintegration for patients with SCI. These findings confirm previous research when discharged early from rehabilitation facilities, patients and caregivers may have less time for education and acquiring necessary knowledge about life after SCI, impacting their longer-term health and well-being.<sup>30</sup> To overcome the issue of poor community reintegration, HCPs recommended the start of virtual care for patients with SCI immediately after discharge from inpatient rehabilitation and reintegrating back into the community. The literature supports the need for virtual services to support health maintenance, facilitate community reintegration, and educate the family caregivers of this patient population.<sup>31</sup>

In this study, majority of the HCPs preferred video-based visits over phone-based appointments, with a subset of HCPs choosing phone-based visits over video-based appointments due to its convenience and easier accessibility. HCPs also noted that with virtual ways of care provision, they could provide maintenance and monitoring pieces of support and educational and counselling-based services. This finding is supported by a randomized trial designed to evaluate the outcomes of telehealth interventions in reducing the incidence of secondary conditions among patients with SCI.<sup>12</sup> This trial also found that the use of technology was a promising approach to continue post-discharge monitoring and educational rehabilitation for this patient population.<sup>12</sup> Our findings regarding using teleSCI for physical therapy are congruent with the existing literature. One pre-post study conducted to examine the effects of a 12-week exercise program coupled with therapist video monitoring for technique and exercise advancement indicated reduced pain and improved function of patients with SCI.<sup>32</sup>

As reported by the HCPs, virtual care services offer an exclusive potential to digitally connect different healthcare providers with the patient and their caregivers simultaneously through a multidisciplinary approach. A recent qualitative study conducted to explore individuals with SCI experiences with and perceptions towards teleSCI services during Covid-19 in British Columbia, Canada, supports the importance of implementing these multidisciplinary virtual health services to improve the understanding of the patient's health condition following SCI.<sup>13</sup> Similar to our findings, this qualitative study raised the issue of the limited application of multidisciplinary approaches within the healthcare system.<sup>13</sup> Regardless of the potential of teleSCI, all HCPs agreed on the constant need for in-person healthcare for community-dwelling adults with SCI. This could simply be attributed to the fact that some severe secondary sequelae

and treatments following SCI are best evaluated and treated in-person, such as complicated bowel and bladder issues, wound care complications, spasticity, respiratory issues, and hands-on physiotherapy services.<sup>13</sup> Our findings are consistent with previous research offering hybridised healthcare where the patient and provider together decide the type of healthcare the patient receives (either in-person or virtual) based on their own needs, as a favourable potential in creating more accessible healthcare for persons with SCI.<sup>33</sup> Together these findings point to a need for future research exploring the use of multidisciplinary approaches and hybrid models of care in managing community-dwelling adults with SCI.

### 3.4.2 Recommendations for Implementing Virtual Clinics

There are several recommendations that can be drawn from the results pertaining to establishing a virtual clinic for patients with SCI as regards to distinguishing the stage where virtual care should begin, to whom virtual services could potentially be delivered, preferred modes of technology, and the content of SCI care that could be integrated into the virtual delivery formats. Table 3 displays the list of recommendations made based HCPs' perspective.

**Table 3.** List of recommendations for implementing virtual clinics for persons with SCI based on HCP's perspectives.

Recommendations for Implementing Virtual Clinics	
<b>Start virtual care immediately after discharge</b>	Introductory educational sessions by rehabilitation therapists could be offered starting in acute care to familiarize patients with the outpatient rehabilitation procedures and community reintegration.
	Providers should consider starting virtual care immediately after discharge from inpatient rehabilitation and reintegrating back into the community.

<b>Offer video-based monitoring, educational, &amp; counselling-based contents of care</b>	Monitoring and educational and counselling-based services could be offered virtually for managing SCI-related routine care (i.e., common bowel and bladder issues, regular skin checks), dietary needs, emotional well-being and sexual health.
	Video-based teleSCI modalities (i.e., videoconferencing, web-based services) could be used for follow-ups, checking for recommendations adherence, simple troubleshooting, medication reviews, and discussing less complicated bowel and bladder, skin-related, and spasticity issues.
	More complicated, and severe bowel and bladder issues, wound care complications, spasticity and respiratory concerns would require to be seen in-person for specific physical examinations.
<b>Assign well-positioned providers for virtual care provision</b>	SCI care coordinators, community navigators, and recreational therapists could use teleSCI to assist patients with SCI in reintegrating back into their communities.
	Three roles of SCI care coordinators, community navigators, and recreational therapists should be trained to virtually connect patients with community resources and assist them with their financial concerns, home adaptations, and source of income modifications if needs are raised.
<b>Use teleSCI in physical therapy</b>	One-on-one physiotherapy consults could be delivered in a virtual format when patients are reintegrated back into their communities, monitoring the exercise programs, troubleshooting, and helping patients to reach specified goals.
	Virtual physiotherapy consults should be applied for those higher-functioning patients; otherwise, it is not recommended for patients with lower functioning, except in the presence of a trained caregiver.
<b>Select appropriate modes of teleSCI</b>	Telephone calls should continue under virtual care delivery as a contingency when video-based visits are not possible.
<b>Use multidisciplinary approach with teleSCI</b>	Multidisciplinary teams consisting of family physicians, physiatrists, physiotherapists, occupational therapists, recreational therapists, dietitians, psychotherapists, social workers, nurses) and community healthcare workers (homecare assistants, gym instructors, community navigators) could virtually connect to maximize the patients' outcomes.
	Virtual care could potentially facilitate the connection of providers with each other, as well as with patients and their caregivers, regardless of where they are located.
<b>Offer hybridised models of SCI care</b>	Hybridised models of care should be offered within the healthcare system to create efficient care pathways, leading to the continuum of care by allowing for triaging and screening to prevent unnecessary contacts.

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### **3.4.3 Study Strengths and Limitations**

The findings of this study provide a rich understanding of virtual care for patients with SCI; however, they represent the HCPs' perspective of the concept. Even though some participants had over 20 years of experience in their roles with patients with SCI, the perspectives of patients with SCI needs to be included to complete the understanding what is needed for a virtual clinic. The comprehensive perspective of all stakeholders, including patients with SCI, would lead to a better understanding of the features and properties needed to plan future virtual clinics for this patient population.

Strengths of the participant group was that the inclusion of multidisciplinary team members with different disciplinary backgrounds (i.e., program managers, occupational therapists, physiotherapists, physiatrists, family physicians, and social workers) allowed for triangulation of data sources. While the recruitment of this study was inclusive of discipline, we did not capture any nurses through participant recruitment. Investigators attempted to contact and sent invitation emails to the nurses several times without response. This study was undertaken during nursing shortages and nurses were under enormous pressure which may explain their lack of response. An outpatient physiotherapist stated that patients with SCI have limited access to nursing services as there is no specific nursing position dedicated to outpatient SCI rehabilitation which may have also contributed. Therefore, future studies can explore SCI rehabilitation nursing roles and propose ways to support an increase in nurses. Another strength

of this study was that the primary investigator debriefed with other co-authors who reviewed the interview guide and participated in the data analysis process, enhancing credibility.

### **3.5 CONCLUSION**

Findings of our study indicated that even though virtual care was identified to be more accessible and convenient regarding care provision for community-dwelling adults with SCI, particularly to those residing in rural areas during the Covid-19 pandemic, there are also many challenges and there is an ongoing need for in-person healthcare to treat and manage patients with SCI.

According to our findings, in a post-pandemic future, stakeholders and policymakers involved with establishing virtual clinics for community-dwelling adults with SCI should consider the value of hybridised (blend of virtual and in-person services) healthcare for this population and uptake of multidisciplinary approaches within the virtual healthcare system.

### **3.6 DISCLOSURE STATEMENT**

The authors report no conflict of interest.

### **3.7 DATA AVAILABILITY STATEMENT**

The data supporting this study's results are available on request from the corresponding author, [JST]. The data are not publicly available because they contain information that could compromise the privacy and confidentiality of research participants.



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**Appendix 3A. COREQ (Consolidated criteria for Reporting Qualitative research) Checklist**

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	56
Credentials	2	What were the researcher's credentials? <u>e.g.</u> PhD, MD	N/A
Occupation	3	What was their occupation at the time of the study?	N/A
Gender	4	Was the researcher male or female?	N/A
Experience and training	5	What experience or training did the researcher have?	N/A
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	57
Participant knowledge of the interviewer	7	What did the participants know about the researcher? <u>e.g.</u> personal goals, reasons for doing the research	57
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? <u>e.g.</u> Bias, assumptions, reasons and interests in the research topic	N/A
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? <u>e.g.</u> grounded theory, discourse analysis, ethnography, phenomenology, content analysis	55
<i>Participant selection</i>			
Sampling	10	How were participants selected? <u>e.g.</u> purposive, convenience, consecutive, snowball	56
Method of approach	11	How were participants approached? <u>e.g.</u> face-to-face, telephone, mail, email	56
Sample size	12	How many participants were in the study?	58
Non-participation	13	How many people refused to participate or dropped out? Reasons?	N/A
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? <u>e.g.</u> home, clinic, workplace	56-57
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	57
Description of sample	16	What are the important characteristics of the sample? <u>e.g.</u> demographic data, date	57
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	57
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	N/A
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	57
Field notes	20	Were field notes made during and/or after the <u>interview</u> or focus group?	N/A
Duration	21	What was the duration of the interviews or focus group?	57
Data saturation	22	Was data saturation discussed?	58
Transcripts returned	23	Were transcripts returned to participants for comment and/or	N/A

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
<b>Domain 3: analysis and findings</b>			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	57
Description of the coding tree	25	Did authors provide a description of the coding tree?	N/A
Derivation of themes	26	Were themes identified in advance or derived from the data?	60
Software	27	What software, if applicable, was used to manage the data?	58
Participant checking	28	Did participants provide feedback on the findings?	N/A
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? <u>e.g.</u> participant number	61-73
Data and findings consistent	30	Was there consistency between the data presented and the findings?	61-73
Clarity of major themes	31	Were major themes clearly presented in the findings?	61-73
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	61-73

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

**Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.**

**Appendix 3B. Letter of Information & Consent form**



**Letter of Information and Consent for Individual Semi-Structured Interviews**

**Stakeholders' perspectives on the development of a virtual clinic  
for patients with SCI**

<b>Local Principal Investigator:</b> Julie Richardson, PhD McMaster University <a href="mailto:jrichard@mcmaster.ca">jrichard@mcmaster.ca</a>	<b>Student Investigator:</b> Shaghayegh Mirbaha, M.Sc. McMaster University <a href="mailto:mirbahas@mcmaster.ca">mirbahas@mcmaster.ca</a>	<b>Co-Investigator:</b> Ada Tang, PhD McMaster University <a href="mailto:atang@mcmaster.ca">atang@mcmaster.ca</a>  Jenna Smith-Turchyn, PhD McMaster University <a href="mailto:smithjf@mcmaster.ca">smithjf@mcmaster.ca</a>
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**What is the purpose of the study?**

The purpose of the study is to consult various stakeholders to identify what they regard as the feasible, essential characteristics, and potential functions of a virtual clinic for community-dwelling adults with Spinal Cord Injury (SCI). We will explore their perceptions and priorities for SCI- associated care, incorporating their feedback to inform the future development of a virtual clinic for the SCI population. This project is based on the inductive qualitative methodological approach of Interpretive Description (ID) described by Thorne.

**Who is being asked to participate?**

You are being invited to participate as you are a healthcare professional, administrative staff, and/or a manager who have at least 1 year of experience working with patients with SCI.

**What does the research involve and how much time will it take?**

You are invited to participate in an individual semi-structured interview to talk about your experience and thoughts on SCI-associated care. We will be asking you about what features and

potential functions are important to you to be included in a future virtual clinic, and what virtual services can help to support patients with SCI in their homes. Each participant will only participate in one interview session. The interview session will take 30-50 minutes. As a result of current circumstances during COVID-19, we will use Zoom platform to collect data, which is an externally hosted cloud-based service. Interview sessions will be video recorded using the Zoom platform and we will be taking additional handwritten notes during the interviews. Participants should not make a recording of the interviews. All interviews will be transcribed. All the identifying information, including full names and Email addresses will be de-

identified and stored securely. Direct quotes of the participants may be included in the manuscript, excluding the participants' identifying information, ensuring your privacy and confidentiality. Additionally, as a participant, you will be allowed to co-enrol in another study while participating in this qualitative study.

### **How long will you be in this study?**

You may be involved in the overall project for up to 6 months, but your involvement in the interview sessions will only take 30-50 minutes.

### **What are the risks and harms of participating in this study?**

We do not believe there are any risks or possible discomfort associated with participating in the interview sessions. However, it is important to note that, although the Hamilton Integrated Research Ethics Board has approved using the Zoom platform to collect data, there is a small risk of a privacy breach for data collected on external servers. If you are concerned about this matter, we would be happy to make alternative arrangements for you to participate, perhaps using telephone lines. Please talk to the leading researcher if you have any concerns. A link to their privacy and policy security is available here ([CLICK HERE](#)).

### **What are the benefits of participating in this study?**

By participating in this study, you may contribute to understanding how we can develop virtual clinic for patients with SCI who live in their homes and communities.

### **Can participants choose to leave the study?**

Your participation in this study is completely voluntary. If you do not feel comfortable to answer some of the questions you are not obliged to, but you can still be part of the study. You may withdraw from the interview sessions at any time by informing the leading researcher, Dr. Julie Richardson, by email ([jrichard@mcmaster.ca](mailto:jrichard@mcmaster.ca)). The data collected prior to you leaving the study will be kept unless you request that it be removed.

### **How will participants' information be kept confidential?**

Every effort will be made to strictly protect all information obtained from you, as well as your confidentiality and privacy. Your anonymity will be always protected during the course of this study. Notes from interviews and video/audio recordings will be stored securely on local servers on McMaster University premises.



All personal information such as your first name and your last name will be removed from the notes, documents, and will be replaced with a random study ID. A list, matching the study ID with your name will be kept in a secure online space apart from your personal file. Please note that the data will be de-identified and aggregated, then published or presented. Seven years after the publication of results, electronically stored data (audio/video recordings) and any other documents, which hold your personal information, will be destroyed, and erased.

In addition to the student investigator (Shaghayegh Mirbaha), Drs. Julie Richardson, Ada Tang, and Jenna Smith- Turchyn only will have access to these video/audio recordings and notes stored securely on local servers at McMaster University.

For the purposes of ensuring the proper monitoring of the research study, it is possible that a member of the Hamilton Integrated Research Ethics Board may consult your research data. By signing this consent form, you authorize such access. Additionally, by participating in this study you do not waive any rights to which you may be entitled under the law.

### **How do I find out about the study results?**

The results of this study will be published in a corresponding journal. If you would like to receive a brief summary of the results, please contact the leading researcher, Dr. Julie Richardson, via email ([jrichard@mcmaster.ca](mailto:jrichard@mcmaster.ca)) to send it to you in a proffered way.

### **Consent Statement**

I have read and understood the information presented in the information letter and the consent form for this study. I have had the purposes, procedures and potential risks and harms of this study explained to me in detail. I have been given sufficient time to read the above information and have had the opportunity to ask questions regarding my participation in this study and to request additional details if needed. I am voluntarily providing written consent agreeing to participate in this study. I understand that my agreement to participate in this study will not affect my decision to stop and withdraw from the study at any time. If at any time I have further questions or concerns about the research, I can contact Dr. Julie Richardson via email ([Jrichard@mcmaster.ca](mailto:Jrichard@mcmaster.ca)).

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HiREB). The HiREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, HiREB, at 905.521.2100 x 42013.

**Stakeholders' perspectives on the development of a virtual clinic  
for patients with SCI**

**Individual Interviews Consent Statement**

**Participant Signature:**

I have read the information provided in the Letter of Information about the study being conducted by Dr. Julie Richardson, Shaghayegh Mirbaha, Dr. Ada Tang, and Dr. Jenna Smith-Turchyn, of McMaster University. I have had the study explained to me and the opportunity to ask questions about my rights and involvement in the study. All of my questions have been answered and I agree to participate.

\_\_\_\_\_  
Name of Study Participant (printed)

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date (DD-MMM-YYYY)

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**Witness Signature:**

My signature means that I have clarified the study to the participant named above. I have answered all questions about their involvement in the study and concerns they may have.

\_\_\_\_\_  
Name of Person Obtaining Consent

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date (DD-MMM-YYYY)

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STATEMENT OF INVESTIGATOR: I, or one of my colleagues, have carefully clarified to the participant the purpose of the above research study. I certify that, to the best of my ability and knowledge, the participant comprehends thoroughly the purpose and methods of the study, as well as the benefits, and risks involved to participants in this study.



## **Appendix 3C. Generated Interview Guide**

### **Interview Guide Questions**

- **Interview Guide for Healthcare professionals (family physicians, nurses, PT, OT, social workers...), administrators, and managers who provide services to patients with SCI**

First of all, thank you for agreeing to take part in this interview. Before starting the interview session, I would like to re-confirm your agreement for participation. Next, I would like to begin this interview by asking you some questions from the first section about your background, profession, and your experience with providing care to patients with SCI.

Following that, there will be five sections that will contain questions about the utility and accessibility of a virtual clinic, potential features and ideal components of a virtual clinic for individuals with SCI, connectivity with peers and caregivers through the virtual space, and finally finishing up the interview by asking you questions to name some facilitators/barriers and advantages/disadvantages of establishing a virtual clinic, all concerning the point of view of healthcare professionals, administrators, and managers.

This interview will take about 30-50 minutes. Please feel free to stop the interview at any time if you want to ask questions or if you wish to stop and withdraw from the interview and the study, respectively. You are not required to answer any questions you do not wish to answer.

For the purpose of this study, I would like to ask your permission to video-record this interview session while ensuring confidentiality.

Are there any concerns or questions before we start the interview?

I will turn on the recorder now ...

### **Interview questions:**

#### **Section 1: Background**

1. Could you tell me about your profession? How are you involved with patients with SCI?
2. For how long have you been involved with patients with SCI? Tell me about your experience with this specific group of patients.

#### **Section 2: The utility and accessibility of a virtual clinic for patients with SCI from Healthcare Professional's Point of View**

3. from an HP (family physicians, nurses, PT, OT, social worker,...)/ administrator/ manager's perspective, what kind of support and care would you think community-dwelling adults who have experienced SCI would want to receive in a virtual clinic ?
  - a. Why?

4. Are there any primary care services or rehabilitative services that you cannot provide to your patients with SCI living in their communities? What are the reasons for not being able to provide them? Can you comment on whether the use of telemedicine and virtual care could have been useful in providing those services?
5. What do you think about the idea of using technology and a virtual platform integrating all the care and support you may require when living in your community? Do you think you would be able to provide all the care you may require through the use of technology? Would anything be missed by having a fully virtual clinic?
6. When (at what time after injury) would you consider the continuum of care for individuals with SCI using the virtual services offered in a virtual platform?
7. What is your opinion about patients' with SCI accessibility and usability of telecommunication tools and technology in receiving care and support?
8. Through which telehealth technology media (i.e., website, application, video conferencing, telephone...) do you think community-dwelling adults with SCI would like to access and use the facilities offered in a virtual telerehabilitation clinic?

### Section 3: Potential Features and Components of the Virtual Clinic

9. What services do you think should be offered in this virtual clinic? What should be included in this space?
10. What programs and interventions do you think this virtual clinic should be offering to community-dwelling adults with SCI? Do you think community-dwelling adults with SCI would like to use self-management programs if integrated into this virtual platform?

### Section 4: Connectivity with Peers and Caregivers Through the Virtual Space

11. Through this virtual space, do you think community-dwelling adults with SCI would want the ability to connect with peers who have lived experience of SCI (peer mentors) or peers who are currently living with SCI? What do you think about peer-to-peer support components being added to this virtual system?
12. Would community-dwelling adults with SCI appreciate the virtual clinic to connect healthcare professionals with caregivers?

### Section 5: Access to Healthcare Professionals

13. Do you think community-dwelling adults with SCI would be interested in connecting with their healthcare professionals through this virtual space?
14. Which of the different approaches for example (different telehealth technology media, including telephone-, video-, or web-based technologies) do you think community-dwelling adults with SCI would prefer to use in communicating with their healthcare professionals?
15. What are the advantages and disadvantages of community-dwelling adults with SCI accessing and connecting with healthcare providers through a virtual stream?
16. How do you think this virtual space would affect the patient-provider relationship and communication?

### Section 6: Facilitators/Barriers & Advantages/Disadvantages of Developing Virtual Clinic for Patients with SCI

17. Overall, what do you think are the advantages of using virtual care for community-dwelling individuals with SCI?
18. What do you think are the disadvantages of using virtual care for community-dwelling individuals with SCI?
19. What factors do you think would facilitate the use of care and support provided through this virtual space?
20. What factors do you think would hinder the use of care and support provided through this virtual space? (what are the barriers?)
21. What do you think are the reasons that community-dwelling adults with SCI might not want to use this virtual clinic?

Thank you so much for answering the questions. This will be the end of our interview session. Do you have any final comments or questions before we end our meeting and interview session?

## **CHAPTER FOUR: DISCUSSION**

#### **4.0 Summary**

The overall purpose of this thesis was to identify models of telehealth services to improve the provision of community-based care for people living with spinal cord injury (SCI). The thesis explored the feasibility, essential characteristics, and potential functions required to implement a virtual clinic for community-dwelling adults with SCI. To accomplish this, two related studies were conducted as part of this thesis. The first study was a scoping review of the literature to identify, describe, and compare models of telehealth services in community-dwelling adults with SCI (chapter 2). This study found telehealth services to be an effective and efficient option for delivering health services to community-dwelling adults with SCI, ensuring continuity of rehabilitation, follow-up after hospital discharge, and early detection, management, or treatment of potential secondary complications following SCI. This review confirmed the importance of a peer support component in telehealth services promoting health behaviours and outcomes among patients with SCI. The second study was a qualitative study using interpretive description methodology where various stakeholder groups (HCPs) were consulted. The objective of this study was to learn about their experiences with telehealth services, their perception of the advantages and disadvantages of using these services, and how these experiences and preferences may influence the future development of a virtual clinic providing care to community-dwelling adults with SCI in Ontario, Canada in a post-pandemic world (chapter 3). The results of this qualitative study indicated that HCPs perceived virtual care to increase access to care over the longer-term, be more convenient, and increase connections between different providers from varied disciplines. Additionally, the qualitative study illustrated the importance of the uptake of multidisciplinary approaches and hybridized care models within virtual healthcare

systems, which could lead to a better understanding of the person's health and secondary SCI-related complications and create more accessible healthcare for persons with SCI, respectively.

#### **4.1 Main contributions**

This thesis work makes distinct and substantive contributions to the discipline of Rehabilitation Science and to the literature focusing on telehealth applications among community-dwelling adults with SCI. Findings from this thesis illustrate the pronounced life-threatening effects of post-injury secondary complications that community-dwelling adults with SCI may experience, and the potential for accessible rehabilitation to prevent and/or manage these secondary complications if primary care services were available.<sup>1</sup> Additionally, the present global Covid-19 pandemic underlies the importance of developing ways, such as the application of telehealth services, to facilitate the continuum of primary care and rehabilitation for patients who need supportive care following community reintegration.<sup>2</sup> Furthermore, this work demonstrates the importance of providing different stakeholder groups (i.e., HCPs) with a voice to participate and collaborate in establishing future virtual clinics for patients with SCI, focussed on improved continuum of care.

The main contributions of each study to the literature are discussed below.

The purpose of *study one* (chapter 2) was to identify, describe, and compare models of virtually-delivered rehabilitative interventions and health services in community-dwelling adults with SCI. This scoping review was the first to directly compare telehealth services available to this patient population in terms of population characteristics, available services, and the studies' outcomes.

The results of our scoping review emphasised multiple key considerations for future studies exploring telehealth services and intervention designs. First, services delivered through video-based modes increased engagement, satisfaction, and clinical outcomes. This may be because video-based service delivery allows for some aspects of physical examination and more face-to-face virtual interaction between the patient and healthcare provider. Second, telehealth interventions encompassing peer support components were widely accepted as a source of social support, indicating the critical role peer support plays in promoting self-management strategies to prevent or manage secondary complications in adults with SCI. Third, community-based telehealth services combined with behavioural techniques and training were effective in establishing self-management strategies and reducing or managing secondary complications by offering adults with SCI ways to remotely self-coordinate their healthcare needs leading to reduced disability after SCI. Additionally, the results indicated virtual strategies increased access, convenience, and interactions with healthcare providers with SCI-related expertise.

The findings from this chapter support the potential for virtual delivery of healthcare services to address limited expert knowledge of SCI-related issues in primary care providers to meet the medical needs of community-dwelling adults with SCI. Existing evidence shows that the treatment and rehabilitation for SCI are long, expensive, and require multidisciplinary approaches.<sup>3</sup> This scoping review highlights the paucity of research on the involvement of multidisciplinary teams in providing telehealth-based support for simultaneously managing multiple secondary complications. future work should aim to promote the collaboration of multidisciplinary teams using telehealth services, comprehensively caring for both the physical and mental recovery of patients with SCI. The findings of our review revealed that, despite the importance of using theoretical approaches in selecting appropriate intervention components and

enhancing the efficacy of behaviour change, current literature lacks attention to the integration of theory in developing telehealth interventions for community-dwelling adults with SCI.<sup>4</sup> Future research should consider implementing an underlying theory or framework to inform services supporting the intended outcomes of these services. The evidence from Study One emphasized the need for more qualitative studies on virtual care for community-dwelling adults with SCI.

The objective of Study Two (chapter 3) was to explore various HCPs' experiences with teleSCI services, their perceptions of the advantages and disadvantages of using these services, and how these experiences and preferences may influence the future development of a virtual clinic providing care to community-dwelling adults with SCI in Ontario, Canada in a post-pandemic world. A recent qualitative study explored experiences of individuals with SCI and perceptions of teleSCI services during Covid-19 in British Columbia, Canada.<sup>5</sup> However, to our knowledge, this is the first qualitative study exploring this issue from the perspective of the HCP.

The results of this study point to several important recommendations pertaining to developing a virtual clinic for patients with SCI. First, participants identified that the optimal time to start virtual care would be immediately after discharge from inpatient care to help support patients when they are reintegrating back into the community. However, under certain circumstances during the early stages of injury in acute care, patients can be offered virtual introductory educational sessions by rehabilitation therapists to accelerate their familiarization with rehabilitation procedures and the community reintegration phase. Community reintegration is a core goal of rehabilitation, as the rehabilitation paradigm has shifted to a biopsychosocial model in which all three aspects of injury, including medical, psychological, and social, are addressed at the same time.<sup>6</sup> Despite the importance of community reintegration in patient care,



the result of this study is congruent with the existing literature demonstrating gaps in the transitional care for patients with SCI who newly transitioned back into their communities.<sup>7</sup> Consequently, the findings of this study suggest that the development of virtual community reintegration programs could be a more accessible way of providing opportunities for patients with SCI to learn about self-management strategies and available community resources, extending rehabilitation within the community beyond inpatient rehabilitation.

Second, this study indicated the valuable contributions of teleSCI services in providing care, mainly when the content includes educating and counselling patients and their caregivers. This is consistent with other literature exploring the feasibility, acceptability, and usability of web-based self-management interventions with educational and counselling components in persons with SCI.<sup>8,9</sup> A quantitative study by Wilde et al.<sup>8</sup> indicated that web-based education and phone-based consultation components of the intervention were highly rated by the persons with SCI using intermittent catheterization for bladder drainage for usefulness, satisfaction, and usability.<sup>8</sup> Our study suggests providers use video-based teleSCI modalities for simple follow-ups, managing less complicated SCI-associated secondary complications (i.e., common bowel and bladder issues (urinary tract infection), skin-related and spasticity complications), checking for recommendations adherence, medication reviews, and answering frequently asked routine care related questions. A recent qualitative study explored the perceptions around virtual care access during the Covid-19 pandemic among patients with chronic diseases in Canada.<sup>10</sup> This qualitative study supports our finding that virtual care is a promising option if patients need to reach their providers for a question or follow-up appointments that do not require an in-person visit.<sup>10</sup> However, we found that the more complicated SCI-related secondary complications such as severe cases of bowel and bladder issues, wound care complications, spasticity, and

respiratory issues must be seen in person for detailed observations and physical examinations. Varied disciplinary providers participated in our study suggest virtual formats of care delivery to deal with emotional well-being, dietary, and sexual health issues that may arise in community-dwelling adults with SCI. Our findings suggest that majority of the healthcare professionals prefer video-based clinical visits and thus should be used as the primary mode of contact with patients with SCI. However, they also suggest that phone communications should be used as a backup plan when videoconferencing is unavailable. This finding is consistent with a recent review exploring considerations when using teleSCI for clinical care, which indicated that better patient-provider interactions occur during video-based clinical visits<sup>11</sup>. However, this recent review also suggested that telephone modes of communication should be preserved when video-based visits are not available or feasible<sup>11</sup>.

Recent qualitative work with a similar objective but from the perspective of persons with SCI identified similar findings; video-based visits were preferred over the phone as the video resulted in overall improved care and interactions with their healthcare professional.<sup>5</sup> The results of our study indicate that a subset of healthcare professionals prefer phone over video-based visits as they experienced it to be more convenient for patients and providers. Furthermore, the results of this qualitative piece revealed that although teleSCI is an alternative way of care provision, it may not be an option for all patients and health issues associated with SCI. For instance, results of the current study reveal that patients with limited access to technology or high-speed internet, physical inaccessibility, and those requiring physical examinations or interventions would need the option of in-person care. Consequently, our study concluded that virtual care would complement in-person care, not replace it. Additionally, the findings of this qualitative study showed that teleSCI expands access to care, especially for persons living in

rural areas, by providing access to expertise while reducing the need to travel long distances to be seen in person. This is consistent with other quantitative and qualitative literature, which showed that telehealth services are a promising option for providing care to persons with SCI who live in rural areas at long distances from specialty care facilities, especially for those where travelling may worsen their medical condition.<sup>5,12</sup> In addition, we found that virtually delivered peer support may be a convenient way of connecting SCI peers.

Overall, findings revealed that virtual care would operate better in persons who are higher functioning (with less severe and lower levels of injury) than lower functioning individuals (with severe and higher levels of injury). Moving forward, hybridized healthcare systems should be implemented to increase the flexibility in selecting care provision formats (in-person or virtual) based on each patient's individualized needs and situation. This study also highlighted the importance of using multidisciplinary approaches within the healthcare systems, where virtual delivery formats facilitate the connection of different providers, including patients' teams of physicians and therapists and community healthcare workers with each other, as well as with the patients and their caregivers.

## **4.2 Strengths and Limitations**

The strengths of this thesis involve the large number of studies included in the scoping review and the inclusion of a diverse and novel group of HCP stakeholders in the second qualitative study. Together, findings provide a rich understanding of potentials for virtual care for patients with SCI in a post-pandemic world. Results of the scoping review were limited by only including studies conducted in high-income countries, mainly in the United States and Canada, limiting the generalizability of the results to the North American healthcare system context. A limitation of

the qualitative study was that the opinions of nurses were not captured. Other interviewees who participated in this study commented on the limited access of patients with SCI to nursing services due to the absence of rehabilitation nurses who mainly specialized in SCI care. This could be a reason why we were unable to recruit nurses involved with patients with SCI in this study.

#### **4.3 Future Research Directions & Recommendations**

Based on our findings, several recommendations for future research can be made:

1. Conduct more randomized controlled trials (RCTs) to gain a more precise outlook on the effectiveness of teleSCI services on health-related patient outcomes among community-dwelling adults with SCI. Consequently, when there are several large-scale trials with similar findings in this field of interest, researchers may consider conducting systematic reviews of randomized trials that offer highest level of evidence.<sup>13</sup>
2. Include multidisciplinary team approaches within the teleSCI interventions to further our understanding of the potential impacts of team-based approaches on the overall outcomes of this patient-specific population.
3. Incorporate theories or frameworks in the development of teleSCI services supporting the intended outcomes of the interventions.
4. Explore the opinions of SCI rehabilitation nurses to be reflected on this subject to overcome the limitation of missing nurses' perspective in our qualitative study.
5. Providers and policymakers should consider offering hybridized healthcare services and the uptake of multidisciplinary approaches within the virtual healthcare system, for community-dwelling adults with SCI.

#### **4.4 Potential Impact for Policymakers and Researchers**

This thesis was part of a larger project aimed at developing a teleSCI clinic to provide primary care and rehabilitative services to community-dwelling adults with SCI in Ontario, Canada, in a post-pandemic world. The experience of conducting a scoping review and a qualitative study towards establishing a virtual clinic for patients with SCI indicated that a mixed scientific research approach is fundamental for this endeavour. The ultimate goal of this thesis was to use the combined findings of the two studies (chapters 2 & 3) to inform policymakers, healthcare professionals, and local/national stakeholders who are engaged in the planning, implementation, and funding process of establishing a virtual clinic for the SCI population. In addition to the recommendations with a healthcare focus outlined in chapter 3, the findings from this thesis suggest points for policymakers to consider for future direction and action.

First, a virtually delivered community-based program should be developed with prioritizing their services promoting continuity of care by offering multiple services such as:

1. Financial assistance and connecting patients with information on funding resources and community supports.
2. Peer system and navigation support to connect patients with peers who have lived experience with SCI and could direct patients to find available community resources that would, unless otherwise, be difficult to find without the help of peers.
3. Assistance with increasing social participation, housing, and employment, thus giving further attention to the social determinants of health.
4. Support with increasing access to available community-based care such as homecare services if needed.

Second, one way to optimize care provision to patients with SCI is to assign the roles of SCI care coordinators, recreational therapists, and community navigators with leadership duties to act as leaders in coordinating care across disciplines and services, promoting continuity of care in the communities. These three roles are well positioned to be accountable for running the community-based programs that must be designed in virtual settings. Future virtual clinics need to design virtual platforms that could bring all varied stakeholders involved with persons with SCI (i.e., clinicians across sectors and disciplines) in one place. This multidisciplinary connection would allow for improved communication and collaboration between care providers, patients, and caregivers. Using technology to build the network of SCI stakeholders with system care pathways to direct patient flow between primary care, community care, and specialist care could enhance access to the appropriate care at appropriate timing. Researchers should focus on the use of telehealth and telerehabilitation with patients with SCI (teleSCI), particularly after the Covid-19 pandemic and increased reliance of healthcare systems on virtual formats of care delivery.<sup>11</sup>

#### **4.5 Concluding thoughts**

This thesis aimed to identify the available models of telehealth services to improve the provision of community-based care for patients living with SCI. Together with our scoping review and qualitative study, our findings provide preliminary evidence for using telehealth services and interventions in patients with SCI. Findings emphasize the need for teleSCI services and programs that could improve access to primary care, community care, and specialist care. The findings of this thesis are congruent with the literature demonstrating the importance of having multidisciplinary team approaches within healthcare systems for patients with SCI.<sup>7</sup>

However, further exploration of how integrating multidisciplinary approaches into virtual care will facilitate care provision and build a network among all SCI stakeholders is needed.

In addition, the qualitative study conducted in this thesis focusing on healthcare professionals' perspectives complements the recent qualitative study conducted in British Columbia, Canada, that explored experiences of persons with SCI and perceptions of teleSCI services during Covid-19.<sup>5</sup> When comparing the results of our study with this pre-existing work, we found that patients and healthcare professionals agree on the advantages, disadvantages, and potential features need to be implemented into the virtual clinics. Likewise, persons with SCI's point of view spotlighted the need to improve connections between different healthcare practitioners through multidisciplinary approaches and introduce hybridized care models to healthcare systems.<sup>5</sup> Regarding the potentials and pitfalls of teleSCI, persons with SCI expressed the opportunities that teleSCI offers to try new healthcare services and concerns related to privacy issues when engaging with teleSCI services, respectively.<sup>5</sup>

Lastly, opportunities exist for promoting virtual care for patients with SCI in the post-pandemic world as, to date, telehealth literature shows that 3even in a post-pandemic world, telehealth will remain a constant component in the routine North American healthcare system.<sup>14</sup> Identifying these opportunities calls for effective communication and collaboration between persons with SCI, stakeholders, including healthcare professionals, researchers, and community members.

## 4.6 Reference

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