Research Article

Improving primary care for persons with spinal cord injury: Development of a toolkit to guide care

James Milligan¹, Joseph Lee¹, Loretta M. Hillier², Karen Slonim¹, Catharine Craven ³

¹Centre for Family Medicine, Kitchener, Ontario, Canada, ²Geriatric Education and Research in Aging Sciences (GERAS), Hamilton, Ontario, Canada, ³Toronto Rehabilitation Institute, Lyndhurst Centre, University Health Network, Toronto, Ontario, Canada

Objective: To identify a set of essential components for primary care for patients with spinal cord injury (SCI) for inclusion in a point-of-practice toolkit for primary care practitioners (PCP) and identification of the essential elements of SCI care that are required in primary care and those that should be the focus of specialist care.

Design: Modified Delphi consensus process; survey methodology.

Setting: Primary care.

Participants: Three family physicians, six specialist physicians, and five inter-disciplinary health professionals completed surveys.

Outcome Measures: Importance of care elements for inclusion in the toolkit (9-point scale: 1 = lowest level of importance, 9 = greatest level of importance) and identification of most responsible physician (family physician, specialist) for completing key categories of care. Open-ended comments were solicited.

Results: There was consensus between the respondent groups on the level of importance of various care elements. Mean importance scores were highest for autonomic dysreflexia, pain, and skin care and lowest for preventive care, social issues, and vital signs. Although, there was agreement across all respondents that family physicians should assume responsibility for assessing mental health, there was variability in who should be responsible for other care categories. Comments were related to the need for shared care approaches and capacity building and lack of knowledge and specialized equipment as barriers to optimal care.

Conclusion: This study identified important components of SCI care to be included in a point-of-practice toolkit to facilitate primary care for persons with SCI.

Keywords: Spinal cord injury, Preventive care, Primary care

Introduction

In Canada, it was estimated that in 2010, 85,556 persons were living with spinal cord injury (SCI), with an estimated 4,259 new cases of SCI per year.¹ SCI represents an insult to the body causing changes to motor, sensory, autonomic, or reflex functioning often resulting in severe physical and sensory deficits.² Common causes include traumatic injury, infection, degenerative or autoimmune or inflammatory processes. Besides the sometimes obvious disabilities (mobility impairments), persons with SCI often have secondary complications

that may not only be detrimental to their health and well-being but also put strain on the healthcare system, (pressure ulcers,³ autonomic dysflexia,⁴ respiratory illness,⁵ spasticity,⁶ neurogenic bowel,⁷ and bladder dysfunction⁸). Emerging evidence also demonstrates that persons with SCI are at increased risk of co-morbid health conditions such as obesity, diabetes and cardiovascular disease.^{5,9–11} The chronic sequela following SCI often results in excessive, yet preventable use of health services.^{12,13} Secondary complications are known to be the primary reason for rehospitalization after initial rehabilitation, particularly in the first year following SCI¹⁴ with half of all Emergency Department visits being for potentially preventable

Correspondence to: Dr. James Milligan, Centre for Family Medicine, 10B Victoria Street South, Kitchener, ON, Canada, N2G 1C5; Ph: (519) 783-0022; Fax: (519) 783-0031. Email: James.Milligan@medportal.ca

(e.g. bladder issues, pneumonia) or low acuity (e.g. pain and complications related to genitourinary devices) conditions that could be managed in primary care.¹² Given the negative health outcomes and high health service utilization, there is a need to improve primary care for persons with SCI.

There is evidence to suggest that persons with SCI receive suboptimal preventative care and have many unmet health care needs.^{15–17} The challenges associated with accessing optimal primary care for those with SCI are well documented including environmental barriers (inaccessible medical buildings, inadequate space, lack of specialized medical equipment),¹⁸ and limited academic preparation and lack of knowledge of SCI health-care issues among primary care providers.^{19,18,20–22} In a qualitative study, family physicians identified knowledge gaps and lack of easily accessible practice tools as challenging their ability to care for persons with SCI.¹⁹ Physicians in this study suggested the need for resources to support primary care such as best practice guidelines and clinical algorithms, with emphasis on tools that were easily accessible, support care at point-of-practice and that are supported/integrated within electronic medical records.

For many of the secondary complications associated with SCI there is a lack of current practice guidelines that are geared specifically to primary care and that are based on level 1 evidence such as large randomized control trials.²³ Despite this, there are resources available to build knowledge on the care of persons with SCI. *Caring for Persons with Spinal Cord Injury* (<http://eprimarycare.onf.org/>) and Actionable Nuggets (www.actionnuggets.ca) are Canadian e-Learning resources that provide critical information to assess and manage key SCI-related complications such as autonomic dysreflexia (AD), neurogenic bladder, neurogenic bowel, respiratory complications, and pressure ulcers. A study evaluating the nuggets, which were distributed to family physicians in a postcard format, found that they were well-received and contributed to increased knowledge of SCI care and improved patient care.²⁴ The Spinal Cord Injury Rehabilitation Evidence (SCIRE) website (<https://www.scireproject.com/>), provides a critical review of the existing literature on many SCI related topics. From Australia, the Spinal Outreach Service Questionnaire (SOS-HQ), provides key questions to ask to prompt preventive care and identify new health concerns.²⁵ While these resources provide invaluable information for managing care, primary care physicians desire easily accessible tools at the point-of practice,¹⁹ such as the Preventative Care Checklist Form,^{26,27} few of which exist to guide SCI primary care.

With this in mind, we developed a point-of-practice template, the SCI Primary Care Toolkit (SCIPCT), for primary care providers (PCP) to guide the assessment and management of patients with SCI. Evidence-informed, this toolkit provides a framework for improving the practice of primary care for patients with SCI that encompasses the multidimensional nature of primary care practice. Care elements for inclusion in the toolkit were generated from a review of the literature, consultation with SCI specialists, and continuous quality improvement cycles (PDSA; plan, do, study, act cycles)²⁸ within a primary care setting. Care elements were also chosen consistent with those contained within a developed SCI Patient Toolkit, a self-management framework for patients.²⁵ The SCIPCT is a periodic preventative health check-up template, which contains indicators for best practice in common areas related to SCI. For example, related to bladder care, there are recommendations to consider ordering an ultrasound for those with neurogenic bladder issues to monitor kidney/bladder health. It is anticipated that this tool would serve to assist physicians to identify and manage preventive care and common SCI-related issues, including the recognition of when to investigate issues further or refer for specialist consultation.

The purpose of this study was to identify a final set of essential components of primary care for patients with SCI for inclusion in the SCIPCT. Moreover, as there are currently varying expectations regarding whether family physicians or rehabilitation specialists (physiatrists) should be responsible for delivering which components of care, this study also aims to clarify these accountabilities and to identify the essential elements of the SCI care that are required in primary care and those that should be the focus of specialist care.

Methods

A survey methodology was used to gather the opinions of health professionals on the essential components of care for patients with SCI. Consistent with the Delphi technique for obtaining consensus,^{29,30} an expert panel of 19 care providers, representing family physicians (N = 7), rehabilitation specialists (N = 7), and non-physician clinicians (N = 5) working in both primary care and rehabilitation, who have known expertise in the care of patients with SCI, was purposefully selected for participation in this study. Invitations to complete the web-based survey were distributed via email, as were two reminders to complete the survey.

Survey respondents were asked to rate the importance of care elements for inclusion in the toolkit using a 9-point scale with 9 representing the greatest level of

importance and 1 the lowest, and to indicate whether family physicians or specialists should be responsible for completing key categories of care represented in the survey: social issues, vital signs (e.g. blood pressure, height, weight), preventive care, bladder/ renal care, bowel care, autonomic dysreflexia, skin care, mobility, pain, neurological/ musculoskeletal function, respiratory care, sexual and reproductive health, and mental health. Written comments for each of these categories were solicited. Information on discipline and number of years in practice was collected to characterize respondents.

Descriptive statistics (frequencies, means, standard deviations) were generated using SPSS 23.0 (IBM Corp). Mean scores for each care category were calculated from the mean scores of each care element within the category. Analysis of variance was used to identify significant ($p < .05$) differences between family physicians, specialists and non-physician clinicians. Written comments were analyzed using descriptive content analysis.³¹

Approval was obtained from the Hamilton Integrated Research Ethics Board, McMaster University.

Results

Fourteen surveys were completed (74% response rate). Surveys were completed by three family physicians (21.4%), six rehabilitation specialists (42.9%), and five primary care-based inter-disciplinary health professionals (35.7%; two nurses, physiotherapist, occupational therapist, chiropractor). Respondents had been in clinical practice an average of 23.6 years (SD = 11.1; range = 4–45).

There were no statistically significant differences between respondent groups in ratings of the importance of care elements so results are presented across all groups (Table 1). The majority of care elements (N = 76; 68%) had mean ratings of importance of 8.0 or greater. Five (4%) care elements had ratings of 6.9 or less, and remaining elements (N = 31; 28%) had mean ratings of importance ranging from 7.0 to 7.9. Ratings were lowest for assessment of marital status, presence of children, performing lying blood pressure, respiratory rate, and height.

The mean scores for each care category were over 8.0 for 8 of the 13 categories; they were highest for autonomic dysreflexia, pain, and skin care and lowest for preventive care, social issues, and vital signs (Table 2).

There was agreement across all respondents that PCPs should assume responsibility for assessing mental health (Table 3). The majority of respondents indicated that PCP should be responsible for assessing

social issues, vital signs, preventive care, and skin care whereas specialists should be responsible for assessing bladder and bowel care, autonomic dysreflexia, mobility, and neurological/ musculoskeletal function. Opinions were generally split for who should be responsible for pain assessment, respiratory care, and sexual and reproductive health. While most PCPs thought they should be responsible for assessing sexual and reproductive health, more specialists thought this should be the specialist's responsibility. More PCPs thought specialists should be responsible for bowel, mobility, and respiratory care, whereas fewer specialists thought they should be responsible for these care categories.

A number of themes were identified in the analysis of open-ended survey comments related to the need for the provision of optimal SCI care (shared care approach, capacity building) and existing barriers to optimal care (lack of knowledge and specialized equipment).

1. Need for a shared care approach to SCI care

It was suggested that SCI care should be a shared care approach with PCP screening for health issues and then consulting with specialists as needed, but should also include inter-professional involvement for some care components. Low volume of patients with SCI and lack of specific knowledge was identified a key rationale for a shared care approach.

“With the low volume of patients we have it seems appropriate for the care to be shared with the specialist.” [Family physician]

“Initial detection [skin care] should be shared responsibility between primary care physician and specialist, whereas best practice assessment and management requires integrated care, multi-disciplinary intervention and ‘thinking beyond the wound’.” [Specialist]

“Occupational therapists and physical therapists should be utilized to help with supporting seating and exercise program.” [Non-physician clinician]

2. Need for capacity building

Capacity building is needed to optimize SCI care at a primary care level, as related to the factors critical to good health outcomes and triggers for specialist referral. Barriers such as lack of SCI specialists, lengthy appointment waits and distance to specialists require there to be improved capacity in primary care.

“You need a lot more CME on this topic [SCI care]” [Family physician]

Table 1 Ratings* of importance of various categories of care to guide the primary care of patients with spinal cord injury.

Care Categories	Number	Mean	SD
<i>Social Issues</i>			
Marital status	14	5.71	2.43
Children (y/n)	14	4.93	2.09
Accommodations (house, apartment, condo, accessible, assisted living)	14	8.00	1.36
Services (attendant, family supports, homecare, other agencies, e.g. SCI Ontario)	14	8.64	0.84
Finances (Employed full-time, part-time; unemployed, Ontario Disability Support Program; Ontario Works, Insurance income)	14	7.36	1.74
Smoking status	14	7.00	2.04
Alcohol use	14	7.14	1.75
Drug use	14	7.36	1.87
<i>Vital Signs</i>			
Blood Pressure sitting	14	7.50	1.83
Blood Pressure lying	13	6.69	1.75
Heart rate	14	7.07	1.69
Respiratory rate	14	6.93	1.73
Height	14	5.50	1.83
Weight	14	7.71	1.64
<i>Preventive Care</i>			
Routine immunizations (e.g. Tetanus, pertussis, measles etc.)	14	8.21	0.89
Influenza vaccine	14	8.36	0.63
Pneumococcal vaccine	14	8.50	0.52
Colorectal cancer screening (as per general population screening)	14	7.50	1.65
Bone Mineral Densitometry	13	8.08	1.26
Cervical cancer screening (pap; as per general population screening)	14	7.57	1.60
Breast cancer screening (mammogram; as per general population screening)	14	7.50	1.65
Prostate cancer screening (rectal exam, PSA; as per general population screening)	14	7.00	1.80
Diabetes screening (every 3 years starting age 40, or other risks- as per guidelines)	14	7.79	1.67
Cholesterol screening (40 in men, 50 in female or post-menopausal or other risks- as per guidelines)	14	7.36	1.55
<i>Bladder/ Renal Care</i>			
Assess type of management (voluntary, intermittent self-catheterization, foley catheter, condom catheter)	14	8.64	0.63
Assess need for cystoscopy for those using suprapubic and foley catheters (due to cancer risk).	14	8.07	1.00
Assess bladder medications	14	8.14	0.86
Assess daily fluid intake	14	7.93	1.07
Assess kidney function (e.g. yearly estimated glomerular filtration rate,eGFR, creatinine, electrolytes?)	14	8.14	0.86
Order ultrasound to assess upper tracts (e.g. every year for first 3 years, then every 2 years?)	14	8.21	0.80
Assess number of urinary tract infections per year	14	8.36	0.75
Assess presence of hematuria (yes/no)	13	7.85	1.44
Assess presence of incontinence (yes/no)	13	8.38	0.87
<i>Bowel Care</i>			
Assess type of management (voluntary; manual removal; digital stimulation; rectal stimulant)	14	8.57	0.76
Assess type of bowel dysfunction (lower motor neuron vs upper motor neuron type bowel)	14	8.57	0.65
Assess Frequency of bowels (e.g. >2/day, 1/day, every 2 days, > every 2 days)	14	7.79	1.12
Enquiring about utilizing gastrocolic reflex	14	7.86	0.95
Assess time of bowel program (e.g. <1 hr, >1 hr)	14	7.93	1.00
Assess if assistance required in bowel care (yes/no)	14	8.07	1.00
Assess stool consistency (e.g. Bristol chart)	14	7.71	1.20
Assess presence of bleeding (yes/no)	14	8.07	1.00
Assess adequate fibre (e.g. 15 g/ day; 5 servings of fruits and vegetables and adequate grains)	14	7.79	1.05
Assess adequate fluid (e.g. men 3.4L/day; women: 2.1L/ day)	14	7.93	0.92
Assess medication use for bowels: stool softeners, stimulant laxatives, suppositories, enemas	14	8.21	0.80
Assess satisfaction with bowel program	14	8.00	1.04
<i>Autonomic Dysreflexia (AD)</i>			
Assess level of patient understanding of signs & symptoms	14	8.64	0.63
Occurrence (yes/no)	14	8.50	0.76
Frequency of occurrence	14	8.57	0.65
Identified triggers	14	8.64	0.63
Medications for treatment	14	8.64	0.50
AD resulting in Emergency Department visits (yes/no)	14	8.57	0.76
AD Wallet card (yes/no)	14	8.36	1.28
<i>Skin Care</i>			
Assess current pressure ulcer / skin concern (yes/no)	13	8.62	0.87
Assess location of pressure ulcer/ skin concern	13	8.62	0.87
Assess treatment	13	8.31	1.03
Assess if Nutrition consult required (yes/no)	13	8.23	0.93
Consider bloodwork (e.g. CBC, BS, albumin)	12	8.08	1.08

Continued

Table 1 Continued.

Care Categories	Number	Mean	SD
Previous pressure ulcers (yes/no)	13	8.38	0.51
Number of previous ulcers	13	8.08	0.76
Assess where/ when previous ulcers	13	8.23	0.73
Treatment of previous ulcers	13	7.92	0.95
Assess practice of skin checks (yes/no)	13	8.48	0.52
Assess practice of pressure relief (yes/no); (e.g. ideal every 15-30mins)	13	8.50	0.67
Mobility			
Assess if ambulatory (yes/no)	14	8.64	0.50
Use of Aids (e.g. none, walker, cane, other)	14	8.64	0.63
Type of wheelchair (manual, electric)	14	8.07	0.92
Age of wheelchair	14	7.57	1.22
Seating assessment (yes/no)	14	7.86	1.03
Date of seating assessment	14	7.43	1.09
Where seating assessment was completed	14	7.14	1.10
Assess exercise status	13	8.08	1.04
Frequency, type, duration of exercise	14	7.93	1.00
Pain			
Assess location	14	8.50	0.52
Pain intensity (0–10 scale)	14	8.43	0.85
Type (nociceptive, neuropathic, complex)	14	8.50	0.65
Effect on function (e.g. relationships, work, sleep, mood)	14	8.36	0.93
Current medications	14	8.43	0.65
Medications previously used	14	8.07	1.00
Non-pharmacological treatments	14	8.07	1.00
Neurological/ musculoskeletal function			
Assess spasticity (yes/no)	14	8.43	0.85
Spasticity location	14	8.36	0.84
Spasticity intensity (0-10 scale)	14	8.14	1.10
Bothersome (yes/no)	14	8.29	0.61
Spasticity worsening in past 12 months (yes/no)	14	8.21	0.58
Spasticity triggers	14	8.36	0.63
Current medications for spasticity	14	8.21	0.80
Effectiveness of medications	14	8.43	0.65
Previous medications	14	8.14	0.77
Assess for change in mobility, function, sensation, pain in past 12 months (yes/no)	13	8.46	0.66
Respiratory Care			
Infections (pneumonia; yes/no)	14	8.57	0.85
Number in past year	14	8.21	0.89
Hospitalizations/ER in past year	14	8.21	0.89
Assess if spirometry performed (yes/no) and results	14	8.07	1.44
Assess daytime somnolence	14	8.07	1.21
Snoring (yes/no)	14	8.00	1.24
Witnessed apneas (yes/no)	14	8.07	1.21
Sleep study performed (yes/no) and results	14	8.14	1.17
Devices used: CPAP (yes/no), others	14	8.14	1.17
Sexual & Reproductive Health			
Satisfied sexually (yes/no)	14	8.21	1.05
Type of sexual activity	14	7.93	1.21
Erectile dysfunction (yes/no)	14	8.14	0.95
Current treatment	14	7.93	1.00
Past treatment	14	7.71	1.07
Barriers to sex	14	7.64	1.08
Contraception (yes/no) and type	14	8.14	1.17
Safe practices (yes/no)	14	8.14	1.17
Fertility desired (yes/no)	14	8.00	1.24
Mental Health			
Assess for depression (e.g. PHQ-2-PHQ-9)**	13	8.23	1.17
Assess for anxiety	13	8.31	1.18
Treatment (yes/no)	13	8.15	1.14
Medications	13	8.23	0.83
Counselling	12	8.50	0.91

SD, standard deviation; PSA, prostate specific antigen.

*9-point scale: 1 = lowest level of importance, 9 = greatest level of importance.

**Patient Health Questionnaire-2 (PHQ-2) and PHQ-9.³⁷

Table 2 Rank ordered mean scores (SD) for each care category (N = 14).

Care Category	Mean Score (SD)
Autonomic Dysreflexia (AD)	8.56 (0.10)
Pain	8.33 (0.19)
Skin care	8.31 (0.23)
Neurological/ musculoskeletal function	8.30 (0.12)
Mental health	8.28 (0.13)
Bladder care	8.19 (0.24)
Respiratory care	8.16 (0.17)
Bowel care	8.09 (0.34)
Sexual and reproductive health	7.98 (0.20)
Mobility	7.93 (0.51)
Preventive care	7.79 (0.48)
Social issues	7.01 (1.19)
Vital signs	6.90 (0.78)

SD, standard deviation.

“The staff need to be educated about this group of individuals and develop consistent care plans and ensure regular follow up/ assessments.” [Non-Physician clinician]

“Great to give family physicians the add-on skill set.” [Specialist]

3. Lack of knowledge in primary care

It was noted there is generally a lack of knowledge about optimal SCI care and limited awareness of available community supports.

“While family physicians are ideally going to assess social issues, we often lack the awareness of

Table 3 Frequency of attributions for most responsible physician for care categories by respondent group (N = 14).

Care Categories	Family physicians (N = 3), n (%)	Specialists (N = 6), n (%)	Non-physician clinicians (N = 5), n (%)	Total (N = 14), n (%)
Social issues				
Family Physicians	2 (66.7)	5 (83.3)	5 (100)	12 (85.7)
Specialists	1 (33.3)	1 (16.7)	0	2 (14.3)
Vital signs				
Family Physicians	1 (33.3)	5 (83.3)	5 (100)	11 (78.6)
Specialists	2 (66.7)	1 (16.7)	0	3 (21.4)
Preventive care				
Family Physicians	3 (100)	5 (83.3)	5 (100)	13 (92.9)
Specialists	0	0	0	0
Bladder/ renal care				
Family Physicians	0	1 (16.7)	3 (60.0)	4 (28.6)
Specialists	3 (100)	5 (83.3)	2 (40.0)	10 (71.4)
Bowel care				
Family Physicians	0	2 (33.3)	3 (60.0)	5 (35.7)
Specialists	3 (100)	3 (50.0)	2 (40.0)	8 (57.1)
Autonomic dysreflexia				
Family Physicians	0	1 (16.7)	4 (80.0)	5 (35.7)
Specialists	3 (100)	5 (83.3)	1 (20.0)	9 (64.3)
Skin care				
Family Physicians	1 (33.3)	2 (33.3)	5 (100)	8 (57.1)
Specialists	2 (66.7)	3 (50.0)	0	5 (35.7)
Mobility				
Family Physicians	0	2 (33.3)	2 (40.0)	4 (28.6)
Specialists	3 (100)	3 (50.0)	3 (60.0)	9 (64.3)
Pain				
Family Physicians	1 (33.3)	1 (33.3)	4 (80.0)	7 (50.0)
Specialists	2 (66.7)	3 (50.0)	1 (20.0)	6 (42.9)
Neurological/ musculoskeletal function				
Family Physicians	0	1 (16.7)	3 (60.0)	4 (28.6)
Specialists	3 (100)	5 (83.3)	2 (40.0)	10 (71.4)
Respiratory care				
Family Physicians	0	2 (33.3)	4 (80.0)	6 (42.9)
Specialists	3 (100)	3 (50.0)	1 (20.0)	7 (50.0)
Sexual & Reproductive Health				
Family Physicians	2 (66.7)	1 (16.7)	4 (80.0)	7 (50.0)
Specialists	1 (33.3)	4 (66.7)	1 (20.0)	6 (42.9)
Mental health				
Family Physicians	3 (100)	6 (100)	5 (100)	14 (100)
Specialists	0	0	0	0

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

specialized supports that may be available for patients with SCI.” [Family Physician]

“In my experience, physicians and rural ER’s do not understand management of urinary tract infections and SCI.” [Non-physician clinician]

“This is the part [bowel care] that we know poorly and defer to specialists.” [Family physician]

4. Challenges in care provision due to lack of specialized equipment

The provision of some aspects of SCI care, such as the assessment of vitals, skin care, and preventive care were viewed as difficult to complete without access to specialized equipment.

Really hard to do this [skin care] if you don’t have the equipment to be able to lift or turn the patient to assess these areas.” [Family physician]

“May be difficult for the family physician to get an accurate weight or lying blood pressure if the room does not have an accessible couch, hoist for transfers etc.” [Specialist]

“Many offices do not have equipment to weigh clients in their wheelchairs; clients cannot transfer to assessment table.” [Non-physician clinician]

Additional care elements for inclusion in the toolkit were also identified including metabolic screening, access to accessible accommodation and attendant care, home safety assessment, and advance care planning.

Discussion

SCI is a complex health condition which requires ongoing attention to a number of care areas, to ensure positive health outcomes for patients. The literature has demonstrated that the annual physical examination used for decades in primary care is not supported in terms of effectiveness and may actually cause harm and undo testing.³² The Canadian Task Force on Preventative Healthcare recommends periodic preventative health visits based on individual risk factors, such as age and gender, as it allows more detailed discussion of screening in regards to each patient’s circumstances.³² In this study, using a consultative process with primary care and rehabilitation specialists, a list of key SCI-related care components were identified to form a point-of-practice tool for the PCP to facilitate identification and intervention intended to be used within the context of each patient’s situation. Based on these findings, a working group was created, consisting of family physicians, specialists, allied health

professionals, and representatives from a consumer advisory group,³³ to further refine the SCIPCT. Changes to the toolkit included the addition of secondary workup for osteoporosis and screening for sleep apnea, as well as the introduction of features facilitating ease of use at point-of-care such as triggering specific actions associated with specific responses and the generation of a summary list of action items upon completion of the tool.

A sample portion of the SCIPCT as revised based on the findings of this current study is presented in Figure 1 (Available as online supplemental material). Given its comprehensiveness, the SCIPCT could potentially be viewed as too lengthy for use in the primary care setting. The amount of time required to complete the SCIPCT varies from 20 to 60 minutes dependent on the number of sections that are applicable to specific patients. As it is meant to trigger enquiry into potentially important areas of care, not all sections may be applicable to all individuals. Also, it is not intended to be completed in a single visit and can be completed over several visits. Integrated into the Electronic Medical Record, ease and speed of completion is facilitated by drop-down boxes and with further sections and prompts appearing dependent on the information that is entered. For example, entering a third urinary tract infection in a 12 month period will prompt consideration of specialist referral.

The toolkit synthesizes best evidence as applied to primary care, bringing awareness to PCP about the health issues that can be managed at a primary level and those that require specialist consultation. This toolkit is unique and offers efficiencies over currently existing tools. Created and tested in primary care, the tool was developed taking into account the constraints and realities of a busy primary care practice. Online resources, though useful, are typically difficult and time consuming to access at the point of practice. Some resources such as the SOC-HQ, were developed primarily as a patient resource, though the latest iteration does combine and prompt some actions for care providers.²⁵ The toolkit described here includes all relevant issues (prevention, immunization, SCI secondary complications) in a single template that when uploaded to the electronic medical record, or even when used in paper-format, is easy to access and represents a ‘one-stop shopping’ tool for SCI primary care. To our best knowledge, there are no other primary care toolkits of this nature. Addressing health care concerns, with the use of the SCIPCT, in a timely manner can potentially help prevent significant problems such as reoccurring bladder infections, bowel dysfunction, fracture prevention, pain, and mental health issues. Identification and

Bladder			
<i>Management Method:</i> ☐ Voluntary ☐ Self-Catheterization ☐ Suprapubic Catheter ☐ Foley Catheter ☐ Condom Catheter	<i>Fluids:</i> ☐ Yes ☐ No ☐ N/A	<i>Hematuria:</i> ☐ Yes ☐ No ☐ N/A	<i>Persistent Incontinence:</i> ☐ Yes ☐ No ☐ N/A
<i>UTI's in the Past Year:</i> ☐ 0 ☐ 1 ☐ 2 ☐ 3 or more	<i>Renal/Bladder US Done in Last 12 Months:</i> ☐ Yes ☐ No ☐ Unknown ☐ N/A		
Bladder Medications:	Bladder Comments:		
Bowel			
<i>Management Method?</i> ☐ Voluntary ☐ Manual Feces Removal ☐ Digital Stimulation ☐ Rectal Stimulation	<i>Routine Length?</i> ☐ Less than 1 Hour ☐ More than 1 Hour ☐ N/A	<i>Frequency?</i> ☐ Daily ☐ Every 2 Days ☐ More than 2 Days	
<i>Presence of Blood in Stool?</i> ☐ Yes ☐ No ☐ N/A	<i>Persistent Incontinence?</i> ☐ Yes ☐ No ☐ N/A	<i>Adequate Fibre (15g/d)?</i> ☐ Yes ☐ No ☐ N/A	
Bowel Medications:	Bowel Comments:		
Autonomic Dysreflexia (AD) A condition of unopposed sympathetic activity occurring in SCI with lesion at T6 or above; characterized by: Increased BP, headache, anxiety, facial flushing, sweating above lesion; goose bumps below lesion, nasocongestion			
<i>Is the Injury Above T6?</i> ☐ Yes ☐ No ☐ Unknown ☐ N/A	<i>Does the Patient Have an Understanding of AD?</i> ☐ Yes ☐ No ☐ N/A		
<i>Has the patient experienced AD?</i> ☐ Yes ☐ No ☐ Unknown ☐ N/A	<i>Frequency of AD?</i> ☐ Rarely ☐ Daily ☐ Weekly ☐ Monthly		
<i>AD Wallet Card?</i> ☐ Yes ☐ No ☐ N/A	<i>ER Visits Due to AD?</i> ☐ Yes ☐ No ☐ N/A		
<i>AD Triggers?</i> ☐ Bladder Issue ☐ Bowel Issue ☐ None ☐ Other:	<i>Medication(s) for AD:</i>		

Figure 1 Sample items from the SCI Primary Care Toolkit flowsheet.

monitoring of these conditions could also potentially reduce preventable and low acuity visits to the ED.

There was great consistency between primary care providers and rehabilitation SCI experts in the importance of the care elements to be included in the toolkit. Those elements with lower ratings of importance are those with which family physicians are most familiar (marital status, children) from their general knowledge of the patient or for which difficulty in assessing is greater than the value derived (lying blood pressure, height). This is also true of the broader care

categories for which social issues and vital signs had the lowest mean scores. Preventive care also had lower mean ratings of importance, which within the context of the more serious secondary complications could be perceived as less important, and may reflect the actual clinical practice of focusing on the more acute or urgent issues and neglecting the regular preventative care or PCPs feeling they have a good understanding of preventative care issues with their patients and do not require specific reminding. However, given the evidence that persons with disabilities are less likely than

able bodied persons to receive preventive care, this category is important to retain in the toolkit.^{16,18,19}

The barriers to optimal primary care identified in this study are well known in the literature;^{17,19,34} the toolkit is an attempt to ameliorate some of these barriers. Sharing care with specialists can ensure optimal care, consistent with a chronic disease management model, allowing the bulk of care to remain at a primary care level and reserving specialist care for the most complex of issues.^{35,36} The creation of clear roles and responsibilities between primary care physicians and specialists, with clear criteria for referrals to specialists and return to primary care, may improve health outcomes and reduce health care costs associated with poor management of SCI.

The SCIPCT can support shared care through its identification of when specialist advice or care is required and by highlighting issues that can be managed effectively in primary care. However, some barriers to care are systemic and cannot be addressed by the toolkit. Optimal SCI care requires access to specialized equipment such as height adjustable examination tables and transfer mechanisms, the absence of which reduces capacity for shared care. Moreover, given the complexity of the health issues experienced by persons with SCI, they require more time to assess and manage than is typically allotted in family practice and the extra time required is not reflected in current remuneration for physicians.¹⁹ The toolkit may potentially better organize and expedite the clinical encounter creating efficiencies within allotted timeframes.

There are a number of limitations to this study. The sample size could be considered low, though it was a considered a purposeful sample of experts at primary care and rehabilitation program levels. SCI is a low prevalence condition and there are a limited number of knowledgeable health care professionals to draw upon. Unlike a true Delphi technique in which consensus is achieved with multiple survey rounds, we elected to use a single survey because the toolkit had previously been within our centre tested with several PDSA (plan, do, study, act) continuous quality improvement cycles²⁸ with specialist input. The survey respondents were all based in Ontario and therefore generalization to other healthcare jurisdictions may not apply, however the literature indicates the issues identified tend to be similar globally. Some of the recommendations would be based on Ontario and Canadian primary care preventative health guidelines and resources available. Persons with SCI were not included in this study as previous and concurrent work has captured their feedback. Future research aims to evaluate the use of the toolkit

and its impact on building family physician capacity to manage SCI care, and reducing preventable health crises and acute care utilization.

Conclusions

This study identified important components of SCI care to be administered at a primary care level that could be used in periodic preventative health visits, as well as challenges to optimal SCI care. Capacity building and shared care approaches were identified as essential for enhancing SCI care at a primary care level.

Acknowledgements

The authors wish to thank the primary care and rehabilitation clinicians and members of the consumer advisory group who have contributed their expertise to the development of this tool.

Disclaimer statements

Contributors None.

Funding This study was funded by the Ontario Neurotrauma Foundation.

Declaration of interest The authors report no declarations of interest.

Conflicts of interest The authors have no conflicts of interest to declare.

Ethics approval This study was approved by the Hamilton Integrated Research Ethics Board, McMaster University.

ORCID

Catharine Craven <http://orcid.org/0000-0001-8234-6803>

References

- 1 Farry A, Baxter D. The incidence and prevalence of Spinal Cord Injury in Canada. Overview and estimates based on current evidence. 2010. Vancouver, BC, Rick Hansen Institute and Urban Futures Institute. Available at: <http://www.urbanfutures.com/reports/Report%2080.pdf>
- 2 Dumont RJ, Okonkwo DO, Verma S, Hurlbert RJ, Boulous PT, Ellegala DB *et al.* Acute spinal cord injury, part I: pathophysiologic mechanisms. *Clin Neuropharmacol* 2001;24(5):254-64.
- 3 Caliri MH. Spinal cord injury and pressure ulcers. *Nurs Clin North Am* 2005;40(2):337-47.
- 4 Bycroft J, Shergill IS, Choong EAL, Arya N, Shah RJR. Autonomic dysreflexia: a medical emergency. *Postgrad Med J* 2005;81(954):232-5.
- 5 Garshick E, Kelley A, Cohen SA, Garrison A, Tun CG, Gagnon D *et al.* A prospective assessment of mortality in chronic spinal cord injury. *Spinal Cord* 2005;43(7):408-16.
- 6 Rabchevsky AG, Kitzman PH. Latest approaches for the treatment of spasticity and autonomic dysreflexia in chronic spinal cord injury. *Neurotherapeutics* 2011;8(2):274-82.

- 7 Krassioukov A, Eng JJ, Claxton G, Sakakibara BM, Shum S. Neurogenic bowel management after spinal cord injury: a systematic review of the evidence. *Spinal Cord* 2010;48(10):718-33.
- 8 Jeong SJ, Cho SY, Oh SJ. Spinal cord/brain injury and the neurogenic bladder. *Urol Clin North Am* 2010;37(4):537-46.
- 9 Ackery A, Tator C, Krassioukov A. A global perspective on spinal cord injury epidemiology. *J Neurotrauma* 2004;21(10):1355-70.
- 10 Sezer N, Akkus S, Gülçin U. Chronic complications of spinal cord injuries. *World J Orthoped* 2015;6(1):24-33.
- 11 Chiodo AE, Scelza WM, Kirshblum SC, Wuermsler LA, Ho CH, Priebe MM. Spinal cord injury medicine. 5. Long-term medical issues and health maintenance. *Arch Phys Med Rehabil* 2007;88(3 Suppl 1):S76-83.
- 12 Guilcher S, Craven BC, Calzavara A, McColl MA, Jaglal S. Is the emergency department an appropriate substitute for primary care for persons with traumatic spinal cord injury? *Spinal Cord* 2012;51(3):202-8.
- 13 Guilcher S, Munce SEP, Couris CM, Fung K, Craven BC, Verrier M *et al*. Health care utilization in non-traumatic and traumatic spinal cord injury: a population-based study. *Spinal Cord* 2010;48(8):45-50.
- 14 Jaglal S, Munce S, Guilcher S, Couris C, Fung K, Craven BC *et al*. Health system factors associated with rehospitalizations after traumatic spinal cord injury: a population-based study. *Spinal Cord* 2009;47(8):604-9.
- 15 Iezzoni LI, McCarthy EP, Davis RB, Siebens H. Mobility impairments and use of screening and preventive services. *Am J Publ Health* 2000;90(6):955-961.
- 16 McColl MA, Jarzynowska A, Shortt SED. Unmet health care needs of people with disabilities: population level evidence. *Disability and Society* 2010;25(2):205-18.
- 17 McColl MA, Aiken A, McColl A, Sakakibara B, Smith K. Primary care of people with spinal cord injury. Scoping review. *Can Fam Physician* 2012;58(11):1207-16.
- 18 Kroll T, Jones GC, Kehn M, Neri MT. Barriers and strategies affecting the utilisation of primary preventive services for people with physical disabilities: A qualitative inquiry. *Health Soc Care Community* 2006;14(4):284-93.
- 19 McMillan C, Lee J, Milligan J, Hillier LM, Bauman C. Physician perspectives on care of individuals with severe mobility impairments in primary care in Southwestern Ontario, Canada. *Health Soc Care Community* 2016;24(4):463-472.
- 20 McColl MA, Forster D, Shortt SED, Hunter D, Dorland J, Godwin M *et al*. Physician experiences providing primary care to people with disabilities. *Healthcare Policy* 2008;4(1):129-47.
- 21 O'Day B, Dautel P, Scheer J. Barriers to healthcare for people with mobility impairments. *Managed Care Quarterly* 2002;10(3):41-51.
- 22 Middleton JW, Leong G, Mann L. Management of spinal cord injury in general practice - part 1. *Aust Fam Physician* 2008;37(4):229-33.
- 23 Thomason SS, Evitt CP, Harrow JJ, Love L, Moore H, Mullins MA *et al*. Providers' perceptions of spinal cord injury pressure ulcer guidelines. *J Spinal Cord Med* 2007;30(2):117-26.
- 24 McColl MA, Aiken A, Smith K, McColl A, Green M, Godwin M *et al*. Actionable nuggets: knowledge translation tool for the needs of patients with spinal cord injury. *Can Fam Physician* 2015;61(5):e240-8.
- 25 Mann L, Middleton JW, Leong G. Fitting disability into practice. Focus on spinal cord injury. *Aus Fam Physician* 2007;36(12):1039-42.
- 26 Dubey V, Glazier R. Preventive Care Checklist Form©. Evidence-based tool to improve preventive health care during complete health assessment of adults. *Canadian Family Physician* 2006;52:48-55.
- 27 Duerksen A, Dubey V, Iglar K. Annual adult health checkup. Update on the Preventive Care Checklist Form©. *Canadian Family Physician* 2012;58(1):43-7.
- 28 Taylor MJ, McNicholas C, Nicolay C, Darzi A, Bell D, Reed JE. Systematic review of the application of the plan-do-study-act method to improve quality in healthcare. *BMJ Quality and Safety* 2014;23(4):290-8.
- 29 Hasson F, Keeney S, McKenna H. Research guidelines for the Delphi survey technique. *J Adv Nurs* 2000;32(4):1008-15.
- 30 Nathens AB, Rivara FP, Jurkovich GJ, Maier RV, Johansen JM, Thompson DC. Management of the injured patient: Identification of research topics for systematic review using the delphi technique. *J Trauma* 2003;54(3):595-601.
- 31 Cavanagh S. Content analysis: Concepts, methods, and applications. *Nurse Practitioner* 1997;4(5):16.
- 32 Birtwhistle R, Bell NR, Thombs BD, Grad R, Dickinson JA. Periodic preventive health visits: a more appropriate approach to delivering preventive services: From the Canadian Task Force on Preventive Health Care. *Can Fam Physician* 2017;63(11):824-6.
- 33 Milligan J, Lee J. Enhancing primary care for persons with spinal cord injury: More than improving physical accessibility. *J Spinal Cord Med* 2015;39(5):496-9.
- 34 Donnelly C, McColl MA, Charlifue S, Glass C, O'Brien P, Savic G *et al*. Utilization, access and satisfaction with primary care among people with spinal cord injuries: a comparison of three countries. *Spinal Cord* 2007;45(1):25-36.
- 35 Ministry of Health and Long-Term Care. Preventing and managing chronic disease: Ontario's framework. Available from: http://www.health.gov.on.ca/english/providers/program/cdpm/pdf/framework_full.pdf.
- 36 Scott IA. Chronic disease management: A primer for physicians. *Intern Med J* 2008;38(6):427-37.
- 37 Arroll B, Goodyear-Smith F, Crengle S, Gunn J, Kerse N, Fishman T *et al*. Validation of PHQ-2 and PHQ-9 to screen for major depression in the primary care population. *Ann Fam Med* 2010;8(4):348-53.