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Research Article

Conception and development of Self-Management indicators to advance the quality of spinal cord injury rehabilitation: SCI-High Project

Gaya Jeyathevan ¹, Susan B. Jaglal ^{1,2,3}, Sander L. Hitzig ^{4,5,6}, Gary Linassi ⁷, Sandra Mills ⁸, Vanessa K. Noonan ⁹, Karen Anzai¹⁰, Teren Clarke ¹¹, Dalton Wolfe ^{12,13}, Mark Bayley ^{1,8,14}, Lubna Aslam ¹⁵, Farnoosh Farahani ¹, S. Mohammad Alavinia ¹, Maryam Omidvar ¹, B. Catharine Craven ^{1,8,14}

¹KITE Research Institute, Toronto Rehabilitation Institute – University Health Network, Toronto, Ontario, Canada, ²Institute of Health Policy Management and Evaluation, University of Toronto, Toronto, Ontario, Canada, ³Department of Physical Therapy, University of Toronto, Toronto, Ontario, Canada, ⁴St. John's Rehab Research Program, Sunnybrook Research Institute, Sunnybrook Health Sciences Centre, Toronto, Ontario, Canada, ⁵Department of Occupational Science and Occupational Therapy, Temerty Faculty of Medicine, University of Toronto, Toronto, Ontario, Canada, ⁶Rehabilitation Sciences Institute, Department of Medicine, Temerty Faculty of Medicine, University of Toronto, Toronto, Ontario, Canada, ⁷Department of Physical Medicine and Rehabilitation, College of Medicine, University of Saskatchewan, Saskatoon, Saskatchewan, Canada, ⁸Brain and Spinal Cord Rehabilitation Program, Toronto Rehabilitation Institute – University Health Network, Toronto, Ontario, Canada, ⁹Praxis Spinal Cord Institute, Vancouver, British Columbia, Canada, ¹⁰GF Strong Rehab Centre, Vancouver, British Columbia, Canada, ¹¹Spinal Cord Injury Alberta, Edmonton, Canada, ¹²Parkwood Institute Research, Lawson Health Research Institute, London, Ontario, Canada, ¹³School of Health Studies, Western University, London, Ontario, Canada, ¹⁴Division of Physical Medicine and Rehabilitation, Department of Medicine, Temerty Faculty of Medicine, University of Toronto, Toronto, Ontario, Canada, ¹⁵Spinal Cord Injury Ontario, Toronto, Ontario, Canada

Context: Although self-management is linked to reduced secondary health complications (SHCs) and enhanced overall quality of life post-spinal cord injury or disease (SCI/D), it is poorly integrated into the current rehabilitation process. Promoting self-management and assuring equity in care delivery is critical. Herein, we describe the selection of Self-Management structure, process and outcome indicators for adults with SCI/D in the first 18 months after rehabilitation admission.

Methods: Experts in self-management across Canada completed the following tasks: (1) defined the Self-Management construct; (2) conducted a systematic search of available outcomes and their psychometric properties; and (3) created a Driver diagram summarizing available evidence related to Self-Management. Facilitated meetings allowed development and selection following rapid-cycle evaluations of proposed structure, process and outcome indicators.

Results: The structure indicator is the proportion of staff with appropriate education and training in self-management principles. The process indicator is the proportion of SCI/D inpatients who have received a self-management

assessment related to specific patient self-management goal(s) within 30 days of admission. The outcome indicator is the Skill and Technique Acquisition, and Self-Monitoring and Insight subscores of the modified Health Education Impact Questionnaire.

Correspondence to: B. Catharine Craven, KITE Research Institute, Toronto Rehabilitation Institute – University Health Network, 206-H 520 Sutherland Drive, Toronto, ON, M4G3V9, Canada; Ph: 416-597-3422x6122. Email: cathy.craven@uhn.ca

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Conclusion: The structure indicator will heighten awareness among administrators and policy makers regarding the need to provide staff with ongoing training related to promoting self-management skill acquisition. Successful implementation of the Self-Management process and outcome indicators will promote self-management education and skill acquisition as a rehabilitation priority, allow for personalization of skills related to the individual's self-management goal(s), and empower individuals with SCI/D to manage their health and daily activities while successfully integrating into the community.

Keywords: Spinal cord injuries, Self-management, Healthcare quality indicator, Health service delivery, Rehabilitation

Introduction

Damage to the spinal cord following injury or disease causes profound changes in nearly all of the body system, the individual's functional abilities, and may affect their ability to independently manage their health. In addition to the initial adjustment to the disability (e.g. sensory, motor, autonomic impairments), individuals with spinal cord injury or disease (SCI/D)¹ also typically experience a number of secondary health conditions (SHCs) and often undergo psychosocial adjustment to their disability,² which may include reduced self-esteem and self-efficacy (one's belief in their abilities to meet the demands of a situation)³ as well as the possibility of dealing with a comorbid mood disorder.² As a result of the SHCs, individuals with SCI/D and their informal care networks (e.g. family members) may mitigate or manage these health conditions that may arise throughout their lives.⁴ Furthermore, length-of-stay (LOS) in tertiary SCI/D rehabilitation has significantly reduced over time,^{5,6} which provides less opportunity to prepare individuals with SCI/D entering the community to attain sufficient knowledge and self-management skills to prevent and/or manage their SHCs.^{5,7}

Common SHCs after SCI/D include urinary tract infections (UTIs), tissue injuries, bowel and bladder dysfunctions, chronic pain, heart disease, sexual disorders, and depression.^{8,9} SHCs can result in service interruptions during rehabilitation, increase morbidity, and contribute to the observed high physician and emergency department (ED) visit rates in this population.¹⁰⁻¹² A recent Ontario (Canada) study found that service interruptions due to SHCs resulted in a mean nine day disruption in inpatient rehabilitation.¹⁰ Furthermore, while many SHCs are preventable, they are key contributors to rehospitalization in the post-acute phase,^{13,14} and are particularly so within the first year post-discharge.⁹ A Canadian study conducted by Noonan and colleagues¹¹ identified that individuals with SCI living in the community have high healthcare utilization; multimorbidity being a significant factor associated with inappropriate healthcare utilization, and together were linked with lower health status. With respect to ED visits, Guilcher and colleagues¹²

reported that there are high rates of ED use for low acuity and potentially preventable SHCs, suggesting that the ED is being used inappropriately among individuals with traumatic SCI. Even after 20 years post-injury, rehospitalization rates continue to be high (*i.e.* more than 30%) due to the cumulative effects of SCI-related SHCs as well as the comorbidities related to aging.¹³ Overall, these studies suggest that individuals with SCI/D are high users of the healthcare system due to their SCI-related health challenges, and are often seeking support in less-than-ideal care settings (e.g. ED); indicating that this population may not be well-prepared to manage their health long-term. Indeed, evidence pointing towards a high prevalence of reported SHCs (e.g. 95.6% of patients with SCI had at least one medical condition at the time of their annual check-up),¹⁵ suggests that the majority of individuals with SCI lack sufficient self-management education and skills.^{16,17} Studies have also reported that family members who provide care to individuals with SCI are not well-equipped to attend to the specialized needs of their injured family member.^{4,18,19}

Considering the health and economic consequences of SCI/D, there have been substantial efforts put forth towards developing interventions enhancing self-management education and knowledge among individuals with SCI/D during rehabilitation care. These interventions have predominately focused on education as the foundation for instilling change,²⁰ and often informed by key self-management components, including problem-solving, decision-making, action planning, self-monitoring/tailoring, resource utilization, and formation of patient-provider partnership.^{21,22} Several studies have reported that patient education promoting self-management has been effective in addressing a range of issues post-SCI, including decreasing the occurrence of SHCs such as pressure injuries, UTIs,²³⁻²⁵ while promoting better emotional well-being and coping skills,²⁶ fostering health promotion,²⁷ and enhancing community participation.^{28,29} Similar to self-management approaches used in other chronic disease groups (e.g. stroke, diabetes, traumatic brain injury), there is no "gold standard" on what

constitutes self-management in a SCI/D population.^{30,31} This lack of consensus of what is self-management reflects that it is a rather complex and multifaceted construct, which makes it challenging to measure self-management outcomes.

Although knowledge related to self-management preparation (e.g. educational interventions) prior to discharge is emerging within Canada,³² there are inconsistent practices across tertiary rehabilitation hospitals, suggesting there is a lack of equity in national care for this population with regards to this domain. Hence, to ensure a broader approach to self-management skill acquisition across the country, efforts are needed, nationally, to address the current gaps in care and advance self-management education and skill acquisition within rehabilitation settings with the goal of improving standards of SCI/D rehabilitation in Canada. Implementation of quality of care indicators can build equity and access to care, identify trends, and inform policy formulation, and monitor rehabilitation programs and care processes.^{33,34} Indicators can measure the structure, process or outcome of health care services and their evaluation can facilitate the sustainability of a high-quality health care delivery system that is based on evidence-informed programs and services.³³ Structure indicators are defined by the properties of the setting in which the health care services occur³⁵ while process indicators describe the specific activities in providing and receiving of care.³⁶ Finally, outcome indicators evaluate health improvements (or deterioration) that can be attributed to the health care or therapy provided, such as mortality, morbidity, health status, health-related quality of life, patient/family/provider satisfaction, and functional ability.³⁶

The SCI Rehabilitation Care High Performance Indicators or “SCI-High Project” is a nationwide endeavor to develop/select, implement and evaluate consensus derived quality of care indicators for 11 domains of rehabilitation prioritized by clinicians, researchers and individuals living with chronic SCI/D. This report describes the processes involved in the selection, development and implementation of structure, process and outcome indicators related to the Self-Management Domain from rehabilitation admission to 18 months thereafter.

Methods

A detailed description of the overall SCI-High Project methods and process for identifying “Self-Management” as a priority domain for SCI rehabilitation care are described in related manuscripts.^{37,38} In addition to the SCI-High investigative team ([\[high.ca\]\(http://high.ca\)\), an external advisory committee and national data strategy committee supported the global project goals and provided oversight regarding the context for implementing all of the planned indicators.](http://www.sci-</p>
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The approach to developing the Self-Management Domain’s structure, process and outcome indicators followed a slightly modified version of the processes described by Mainz,³⁹ which included the following planning and development phases: (a) formation and organization of the national and local Working Groups; (b) defining and refining the key domain and specific target construct; (c) providing an overview/summary of existing evidence and practice; (d) developing and interpreting a Driver diagram (*i.e.* visual display of a high-level quality improvement goal, and a set of underpinning factors/goals⁴⁰); (e) selecting indicators; and (f) pilot testing and refinement of the domain-specific structure, process and outcome indicators. Throughout these processes, a facilitated discussion occurred amongst the domain-specific Working Group and the SCI-High Project Team to capitalize on the relevant expertise of the different stakeholders on the topic while ensuring that the broader goals of the SCI-High Project were aligned across the other 10 domain Working Groups (as appropriate). The selected indicators will be integrated into the larger SCI-High Project framework to create a group of indicators and related best practices for routine implementation within a single rehabilitation program with project-wide report cards enabling cross site comparisons of structure, process and outcomes.

Self-Management Working Group

Experts in self-management and relevant stakeholders were invited to participate in the SCI-High Project as members of the domain-specific Working Group based on their practical or empirical knowledge of SCI/D rehabilitation, self-management, health service delivery and patient education. The group was composed of practitioners, rehabilitation scientists, patient and family educators, partners from community organizations, policy leaders, researchers, and a stakeholder with lived experience. The Working Group met 13 times via conference call over an 18-month period; totaling 17 h of discussion related to the development of the indicators to refine the indicators and discuss manuscript preparation. Outside of the formal meeting, individual members of the Working Group completed an additional review of the prepared materials, shared resources and/or practice standards with one another, or conducted independent evaluations of the proposed indicators.

Driver diagram and construct definition

The selection of Self-Management as a domain of interest for developing indicators emerged from a consensus-building activity to select the broader set of domains being pursued within the overarching SCI-High Project.³⁸ This process involved a systematic search to collect information about SCI/D rehabilitation care related to self-management, identification of factors that influence the outcome of rehabilitation interventions, and a scoping synthesis of the data acquired. The MEDLINE, EMBASE and CINAHL databases were searched using the combination of the terms “self-management” and “spinal cord injury” (similar terms were selected for each database). This information was then used to create a Driver diagram to illustrate known drivers or factors that impact self-management among individuals with SCI/D (Fig. 1). The Driver diagram helped to organize change concepts as the Working Group discerned “what changes can we make, that will result in goal attainment”. The branches in red within the final Driver diagram represent the main areas that were the focus for development of indicators based on experts’ opinions.

Following review of the systematic searches, discussions, and multiple refinements of the Driver diagram, the group agreed that self-management skill acquisition to help individuals with SCI/D to manage their health and daily activities towards successful

community integration was the driver most likely to advance SCI/D rehabilitation care in the near term. Based on this discussion, and reflection upon current terminologies, the following construct definition was created:

Self-management relates to the tasks and skills that an individual must undertake to live well with a SCI/D. These tasks and skills include having or gaining the confidence and problem-solving abilities to deal with medical management, role management and emotional management.

Selection of indicators

Consistent with the methodology used in the SCI-High Project, the Working Group was asked to develop/select at least one indicator each for structure, process and outcome in relation to the Self-Management Domain. The Project Leaders stipulated that the indicators should be relevant, concise and feasible to implement (10 min or less), and aligned across the structure, process and outcome to achieve a single substantive advance in SCI/D rehabilitation care. The indicators could be measured using established or new measurement tools (*i.e.* questionnaires, data collection sheets, laboratory exams, and medical record data), depending on the requirements and feasibility of a given indicator. The Working Group felt that the

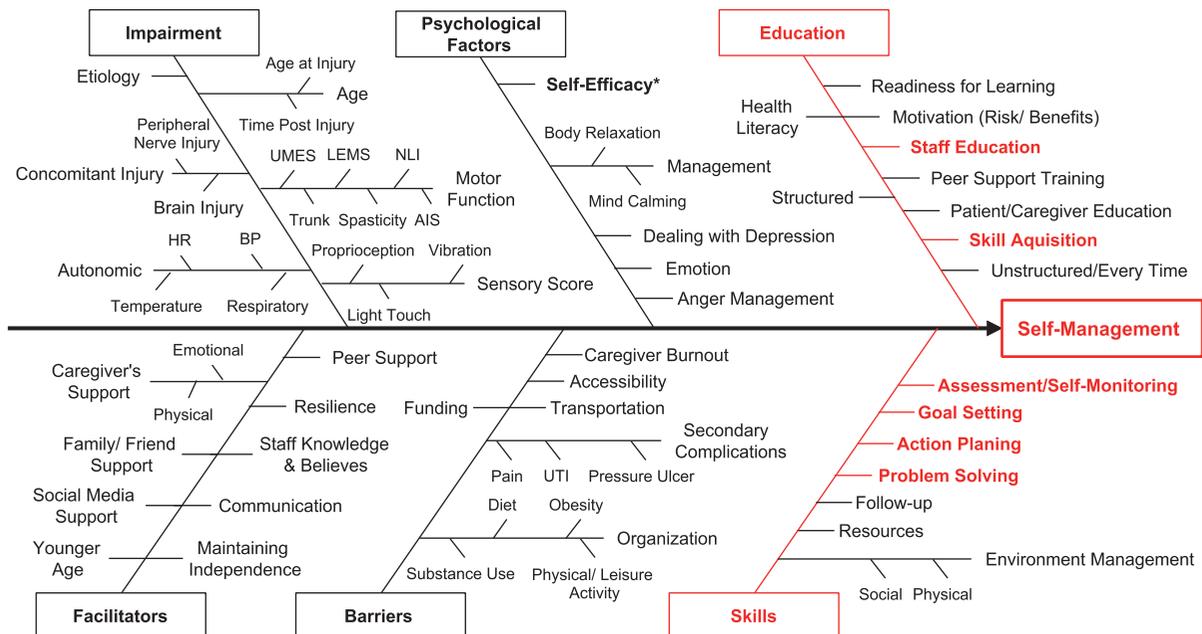


Figure 1 Self-management Driver diagram. The impairment branch is common to the 11 SCI-High Project domains. UEMS: Upper-Extremity Motor Score, LEMS: Lower-Extremity Motor Score, NLI: Neurological Level of Injury, AIS: ASIA Impairment Scale, HR: Heart Rate, BP: Blood Pressure, UTI: Urinary Tract Infection. *: Self-Efficacy, although relevant in Self-Management, has been used as an outcome measure for the Community Participation Domain (66).

process indicator should inform the specific self-management skills required by individuals with SCI/D post-discharge into the community (e.g. gathering information, medication management, symptom management, self-advocacy, etc.). The Working Group reviewed several skill inventories and identified constructs of importance prior to selecting the process indicator. The Working Group’s intent was to create a process indicator that would inform the outcome indicator and vice-versa, yet allow for individualized goal setting and assure the selected indicators would be of relevance across a variety of individual patient goals. The time constraints for indicator assessment also drove the Working Group’s decision making and indicator selection. The Working Group chose to refine an existing tool (SCI Self-Management Evaluation Tool (SCI-SMET)) acceptable to patient’s with SCI/D rather than creating a new tool de novo.

Indicator piloting and refinement

The refinement of the indicators related to Self-Management were primarily driven by the impetus to promote self-management skill acquisition to ensure individuals with SCI/D can manage their health and daily activities toward successful community integration (as depicted in Fig. 1 and the construct definition). The Working Group focused on the structure indicator in order to inform the development of the process and outcome indicators. To promote self-management among people with SCI/D, the feasibility of the structure and process indicators for the Self-Management Domain was pilot tested. The indicator was reviewed and refined through multiple quality improvement Plan-Do-Study-Act (PDSA)³⁴ cycles for quick qualitative evaluations, feedback and refinement. The structure indicator pilot data will be used to create a consensus definition of self-management “training and skills”.

Results

Indicator development

The indicators selected by the Self-Management Working Group are shown in Table 1, which specifies the type of indicator, denominators, and timing of measurement for each of the selected indicators.

The structure indicator is a self-management staff self-assessment tool, which will be completed by any SCI rehabilitation Health Care Professionals (HCP) or peer mentor to assess their self-management training, skills, level of comfort and confidence to effectively provide self-management support to individuals with SCI/D (structure indicator; Fig. 2).

The process indicator related to Self-Management is the proportion of SCI/D inpatients who have received a self-management assessment within 30 days of admission (process indicator; Fig. 3). The Working Group refined the SCI-SMET (i.e. based on the above-mentioned requirements and restrictions) of the original tool developed by Dr. Gary Linassi (author) and colleagues from the Saskatchewan Health Authority. The SCI-SMET was developed with specific self-management constructs in mind, including: goal setting, problem-solving, action planning, and self-monitoring. *Goal setting* is the process by which one identifies specific goals and determines how they will be achieved.⁴¹ *Problem-solving* implies a behavioral process which (a) makes available a variety of response alternatives for dealing with a problematic situation and (b) increases the probability of selecting the most effective response from among these alternatives.⁴² *Action planning* denotes *where, when, and how* a goal will be implemented and help individuals plan the specific actions they will take to achieve their overarching goal.⁴¹ Finally, *self-monitoring* is part of managing many chronic conditions, and comprises of two major attributes or central components: (1) awareness of bodily symptoms, sensations, daily activities, and

Table 1 Selected structure, process and outcome indicators for the Self-Management Domain.

| Indicator | Denominator | Indicator Type | Time of Measurement |
|--|--|------------------------|---|
| Proportion of staff with appropriate education and training in self-management principles | Total number of healthcare professionals within the tertiary SCI rehabilitation team | Structure | Annual |
| Proportion of SCI/D inpatients who have received a self-management assessment (e.g. SCI Self-Management Evaluation Tool) | Total number of inpatients per fiscal year | Process | 30 days within admission |
| Modified Health Education Impact Questionnaire (m-heiQ) | Total number of inpatients per fiscal year | Outcome – Intermediary | Prior to rehabilitation discharge |
| Modified Health Education Impact Questionnaire (m-heiQ) | Total number of inpatients per fiscal year | Outcome – Final | 18 months post rehabilitation admission |

SCI-High Self-Management: Staff Self-Assessment Tool

This tool should be filled out by all inpatient and outpatient employees (full-time, part-time, and casual) participating in the provision of self-management services for patients with spinal cord injury or disease (SCI/D) in your organization. We anticipate this will take approximately 6-8 minutes to complete. The information collected will be used to inform the quality of rehabilitation care for individuals with SCI/D.

Self-management relates to the tasks and skills that an individual must undertake to live well with a spinal cord injury/disease. These tasks and skills include having or gaining the confidence and problem-solving abilities to deal with medical management, role management and emotional management.

1. Date: / / (YY/ MM/DD)

2. Please provide your initials:

3. Please identify your parent organization: _____

4. Please identify your profession:
 - Community Support Worker/Personal Support Worker
 - Occupational Therapist
 - Occupational Therapy Assistant
 - Patient/Family Educator
 - Peer mentor
 - Physiotherapist
 - Physiotherapy Assistant
 - Practice Leader
 - Psychologist
 - Psychometrist
 - Psychotherapist

Physician

 - Family physician
 - Neuropsychiatrist/Psychiatrist
 - Physiatrist

Nurse

 - Nurse Practitioner
 - Registered Nurses
 - Registered Practical Nurses- Respiratory Therapist
- Social Worker
- Speech Language Pathologist
- Spiritual Care
- Other: _____

Figure 2 SCI-High self-management staff self-assessment tool. Structure indicator SCI-High self-management self-assessment tool to assess self-management training and skills of SCI rehabilitation healthcare professionals and peer mentors involved in the provision of self-management services.

cognitive processes and (2) measurements, recordings, or observations that inform cognition and provide information for independent action or consultation with care providers.⁴³ Together, these constructs could drive behavior change and enhance patient self-management. The SCI-SMET allows HCPs to document and have facilitated conversations regarding specific

patient self-management goals, as well as a level of confidence in carrying out self-management behaviors and barriers to self-management.

With respect to the outcome indicator, several meetings were held discussing relevant, valid and reliable tools to measure the effect of self-management/patient education programs (e.g. self-management

5. Please specify if you are a volunteer or employee:
 - Employee
 - Volunteer
6. If you are an employee, please identify your type of employment:
 - Full-time
 - Part-time
 - 1 day/week
 - 2 days/week
 - 3 days/week
 - 4 days/week
 - Casual
7. Please identify your gender:
 - Male
 - Female
 - Other
 - Prefer not to disclose

Work Experience:

8. What part of the health care system do you currently work in? (check all that apply)
 - Inpatient spinal cord rehabilitation
 - Outpatient spinal cord rehabilitation
 - Community service provision
 - Peer support
 - Other: _____
9. How many years (or months) of work experience related to SCI/D do you have?

| | |
|--|----------------|
| | _____ Year(s) |
| | _____ Month(s) |
10. On average, how many SCI/D patients did you provide self-management support to within the last 3 months?

| | |
|--|-------|
| | _____ |
|--|-------|

Training and Resources:

11. On a scale of 1-5, how convinced are you that it is important to support patients / clients in becoming effective self-managers?

| | | | | |
|---------------|---|---|---|---------------------|
| 1 | 2 | 3 | 4 | 5 |
| Not Convinced | | | | Extremely Convinced |
12. Have you received training in the area of self-management support?
 - Yes
 - No
 - Not Sure

Figure 2 Continued

skills acquisition; refer to [Table 2](#) for the outcome measures table). Following a review of available literature, a relevant tool was agreed upon: Health Education Impact Questionnaire (heiQ).⁴⁹ The heiQ is a user-friendly, appropriate and psychometrically sound tool designed to measure the effect of self-management/health education programs based on patients'

perspectives. The heiQ offers a new approach to measuring behavioral, cognitive and emotional responses and fills a vital gap in patient-centered outcome assessment related to self-management. Studies using heiQ found that it captured various aspects (*i.e.* dimensions mentioned below) other than standard measures typically used to assess self-

13. Have you participated in any of the following educational opportunities for the purpose of learning about self-management in SCI? *(please select all that apply and include course details)*

| Course | Time to Complete (hours of training) | Online or In-Person | Course Conductor/ Organizational Sponsor | Was this Course Part of Maintenance of Certification? | Was this Course Accredited? (received certificate) |
|--|---|---------------------|---|---|---|
| <input type="checkbox"/> Motivational interviewing | | | | | |
| <input type="checkbox"/> Choices and Changes: Clinician Influence and Patient Action | | | | | |
| <input type="checkbox"/> Stanford Chronic Disease Self-Management Program | | | | | |
| <input type="checkbox"/> Brief Action Planning | | | | | |
| <input type="checkbox"/> Peer Mentor Training | | | | | |
| <input type="checkbox"/> Goal Setting / Action Planning / Problem Solving | | | | | |
| <input type="checkbox"/> Accessing Resources and System Navigation | | | | | |
| <input type="checkbox"/> Stages of Change | | | | | |
| <input type="checkbox"/> Teach Back | | | | | |
| <input type="checkbox"/> Other: _____ | | | | | |
| <input type="checkbox"/> Other: _____ | | | | | |

14. Have you facilitated any self-management support activities in a health care organization in the last year?

- Yes (please specify below):
 - Special workshop
 - Lunch and learn
 - Small group presentation
 - Other (please specify) _____
- No
- Not Sure

15. On a scale of 1-5, how confident are you that you can effectively provide self-management support to patients / clients with SCI?

| | | | | |
|---------------|--------------------|---------|-----------|---------------------|
| 1 | 2 | 3 | 4 | 5 |
| Not Confident | Somewhat Confident | Neutral | Confident | Extremely Confident |

Figure 2 Continued

management,⁶⁵ such as self-efficacy (e.g. Moorong Self-Efficacy Scale (MSES)). Furthermore, the Working Group felt that since the Community Participation Domain (manuscript submitted for publication)⁶⁶ will use the MSES to assess and collect data on self-efficacy of individuals with SCI/D as the outcome measure, the Self-Management outcome indicator should focus on a tool that measures the effect of self-management/health education programs. The heiQ consists of eight independent dimensions, including: Positive and Active Engagement in Life; Health Directed

Behaviour; Skill and Technique Acquisition; Constructive Attitudes and Approaches; Self-Monitoring and Insight; Health Service Navigation; Social Integration and Support; and Emotional Wellbeing.

The Working Group felt two of the dimensions and their related items (Skill and Technique Acquisition, and Self-Monitoring and Insight) were the most relevant to our goal of acquisition of specific self-management skills required by individuals with SCI/D, which is consistent with the process indicator tool (outcome

16. Please rate how confident you feel about each of the following statements from NOT CONFIDENT to EXTREMELY CONFIDENT.

| I am confident that ... | Not Confident | Somewhat Confident | Neutral | Confident | Extremely Confident | Not Applicable |
|---|---------------|--------------------|---------|-----------|---------------------|----------------|
| I can identify which clients would benefit from Self-Management support. | | | | | | |
| I can work with clients to increase their motivation to change. | | | | | | |
| I can work collaboratively with clients to set achievable goals. | | | | | | |
| I can work collaboratively with clients to develop action plans. | | | | | | |
| I can assess my clients' confidence in their ability to follow-through with their action plans. | | | | | | |
| I can assist clients to problem-solve and/or collaboratively problem solve with them. | | | | | | |
| I can follow-up on clients' action plans. | | | | | | |
| I can work with clients to increase their self-efficacy about managing their health conditions. | | | | | | |
| I can support my colleagues in implementing Self-Management support strategies | | | | | | |

17. Please rate how confident you are in your ability to use each of the following Self-Management support strategies in your practice?

| | Not Confident | Somewhat Confident | Neutral | Confident | Extremely Confident | Not Applicable |
|------------------------------|---------------|--------------------|---------|-----------|---------------------|----------------|
| Readiness to Change | | | | | | |
| Accessing Reliable Resources | | | | | | |
| Ask-Tell-Ask | | | | | | |
| Closing the Loop | | | | | | |
| Setting Goals with Clients | | | | | | |
| Making Action Plans | | | | | | |
| Confidence Ruler/Scale | | | | | | |
| Motivational Interviewing | | | | | | |
| Problem Solving | | | | | | |
| Follow-up/Accountability | | | | | | |
| Teach Back | | | | | | |

Figure 2 Continued

indicator; see Table 3 for the modified heiQ). The participants will be asked to rate their confidence in their ability to complete specific tasks on 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). The Skill and Technique dimension captures the knowledge-based skills and techniques that help patients manage disease-related symptoms and health problems more effectively. High scores are characteristic of an individual who has highly developed skills related to symptom relief and techniques to manage their own health. The Self-Monitoring and Insight dimension captures the patients'

ability to monitor their conditions, and their physical and/or emotional responses that lead to insight and appropriate actions to self-manage. High scores identify self-monitoring, self-management, setting reasonable targets, and insight into living with a health problem.⁴⁹ Recognizing that individuals with SCI/D are likely to continue to acquire self-management skills post-discharge, the Working Group decided that the two time points for completing the modified heiQ would be prior to rehabilitation discharge and 18 months post-rehabilitation admission. The heiQ has high construct

SCI Self-Management Evaluation Tool

Self-management: the tasks and skills that a person must do to live well with a spinal cord injury or disease. These tasks and skills include having or gaining the confidence and problem-solving abilities to deal with emotions, thoughts and behaviors in different situations.

We are interested in your thoughts and experiences about health care self-management. This survey will take approximately 7-10 minutes to complete.

What is your most important self-management goal?

Please complete this questionnaire about your most important self-management goal

1. What are the first three digits of your home postal code?

| | | |
|--|--|--|
| | | |
|--|--|--|

2. After discharge, do you plan to have anyone help you with your care?

- Yes
- No (skip to Question 4)

3. If yes, please check all that apply:

- Spouse/Partner
- Child/Children
- Parents
- Siblings
- Friend/Roommate
- Paid caregiver (e.g. attendant, nurse, paid by government, paid out of pocket)
- Inpatient rehab services
- Other: _____

A. GATHERING INFORMATION

4. How strongly do you agree or disagree with the following statement?

| | | | | |
|--|--------------------------------|-------------------------------|-----------------------------|--------------------------------------|
| I am able to look for new information to help me manage my spinal cord injury: | | | | |
| <input type="radio"/> Strongly disagree | <input type="radio"/> Disagree | <input type="radio"/> Neutral | <input type="radio"/> Agree | <input type="radio"/> Strongly agree |

5. How often do you look for new information to help manage your spinal cord injury?

- Daily
- At least weekly
- At least monthly
- A few times a year
- Never
- Not Applicable

Figure 3 SCI self-management evaluation tool (SCI-SMET). Process indicator SCI-SMET for healthcare professionals to document specific patient self-management goals and assess level of confidence in carrying out self-management behaviors and barriers to self-management.

validity and has reliable measures of key dimensions related to self-management behaviors, which could be easily incorporated into assessment practice in a rehabilitation setting in order to advance goals of self-management programs.^{65,67,68}

Self-Management indicator piloting Pilot study results- structure indicator

The pilot data regarding the self-management training and skills includes results from six SCI rehabilitation HCPs who completed the staff self-assessment

SCI Self-Management Evaluation Tool

6. Where do you find trusted information about spinal cord injury and/or its related health issues? (please check all that apply)

- Internet
- Support Organizations
- Printed Documents (books, magazines, guidelines, bulletins, etc.)
- Healthcare Providers
- Peers
- Other: _____
- Not Applicable

7. List the information you search for most often about your self-management goal.

B. MEDICATION MANAGEMENT

8. How strongly do you agree or disagree with the following statement?

| | | | | |
|---|--------------------------------|-------------------------------|-----------------------------|--------------------------------------|
| I feel I have a good understanding of my medications: | | | | |
| <input type="radio"/> Strongly disagree | <input type="radio"/> Disagree | <input type="radio"/> Neutral | <input type="radio"/> Agree | <input type="radio"/> Strongly agree |

9. How often do you spend time looking after your medications (see examples in question 10)?

- Daily, based on my needs
- Weekly, based on my needs
- A few times a month, based on my needs
- Once a month, based on my needs
- Less than once a month
- I do not spend any time managing my medications (skip to Question 11)
- I do not take any medications (skip to Question 11)

10.If you look after your own medications, do you... (please check all that apply)

- Ask your health care provider for certain medications or supplements yourself
- Suggest the dosage of medication to your healthcare provider
- Suggest when to take them to your healthcare provider
- Suggest how often you should be taking them to your healthcare provider
- Change the dose, timing or frequency of medication yourself
- Provide feedback to your prescriber on response and complications
- Suggest new medication to your healthcare provider
- Renew or refill your medications or supplements yourself
- Other: _____

Figure 3 Continued

tool. The tool was completed within an average of 14 min. The majority of the participants reported they received training in the area of self-management support, and have participated in educational opportunities for the purpose of learning about self-management in SCI (e.g. Clinician Influence and Patient Action, Stages of Change, Teach Back, etc.). Regarding the level of confidence in effectively providing self-management support to patients with

SCI, the majority reported they are confident (on a scale from 1-not confident to 5-extremely confident). Feasibility issues and challenges experienced included: (1) more time required when tracking down specific education and training-related information (e.g. courses attended); (2) tool was not applicable considering the individual did not receive formal training due to limited work experience; (3) required clarifications (e.g. how much time needs to

SCI Self-Management Evaluation Tool

C. SELF-MONITORING/SYMPTOM MANAGEMENT

11. How strongly do you agree or disagree with the following statement?

| | | | | |
|--|--------------------------------|-------------------------------|-----------------------------|--------------------------------------|
| I am able to check the symptoms related to my spinal cord injury | | | | |
| <input type="radio"/> Strongly disagree | <input type="radio"/> Disagree | <input type="radio"/> Neutral | <input type="radio"/> Agree | <input type="radio"/> Strongly agree |

12. How strongly do you agree or disagree with the following statement?

| | | | | |
|--|--------------------------------|-------------------------------|-----------------------------|--------------------------------------|
| I am able to look after the symptoms related to my spinal cord injury: | | | | |
| <input type="radio"/> Strongly disagree | <input type="radio"/> Disagree | <input type="radio"/> Neutral | <input type="radio"/> Agree | <input type="radio"/> Strongly agree |

13. Do you check for or record any of the following? (please check all that apply)

- Blood pressure
- Skin condition
- Bowel management
- Bladder management
- Pain
- Physical activity
- Mood
- Other: _____
- Not Applicable

14. Do you keep a health diary or journal?

- Yes, and I discuss with my healthcare provider
- Yes, but I do not discuss with my healthcare provider
- No, I do not keep a health diary or journal

15. Are you using a mobile app or web-based resource to monitor your health or related health issues?

- Yes
- No (skip to Question 18)

16. If yes, list all that apply and what it helps you look after?

| Mobile app/web-based resource | What does it help you with? |
|-------------------------------|-----------------------------|
| | |
| | |
| | |

17. Who do you talk to if you are concerned about your symptoms?

Figure 3 Continued

be allocated with each patient to be considered providing self-management support); and (4) difficulty completing the tool in electronic form.

Pilot study results- process indicator

To optimize workflow (*i.e.* conducting self-management assessments), the feasibility of the SCI-SMET

was pilot tested in an adult outpatient clinic at a tertiary SCI rehabilitation hospital in a large urban center. Consecutive patients attending routine follow-up appointments, as well as inpatients, were approached by trained evaluators to complete the tool. The pilot data includes results from eight patients. The tools were completed within an average of 7–10 min. Noted

SCI Self-Management Evaluation Tool

D. EMOTIONAL MANAGEMENT

18. How strongly do you agree or disagree with the following statement?

| | | | | |
|---|--------------------------------|-------------------------------|-----------------------------|--------------------------------------|
| I am able to look after my emotional and mental well-being (i.e. anger, stress, anxiety, or depression) | | | | |
| <input type="radio"/> Strongly disagree | <input type="radio"/> Disagree | <input type="radio"/> Neutral | <input type="radio"/> Agree | <input type="radio"/> Strongly agree |

19. What/who is most helpful to you in managing your emotions?

E. SOCIAL SUPPORTS

20. How strongly do you agree or disagree with the following statement?

| | | | | |
|---|--------------------------------|-------------------------------|-----------------------------|--------------------------------------|
| I am able to get social support (e.g. healthcare professional, family members, peers) to help me look after my spinal cord injury | | | | |
| <input type="radio"/> Strongly disagree | <input type="radio"/> Disagree | <input type="radio"/> Neutral | <input type="radio"/> Agree | <input type="radio"/> Strongly agree |

21. How important are the following people to you in helping you self-manage? (check the most appropriate response for each social support)

| | Very Important | Important | Neutral | Moderately Important | Not at all Important |
|---|----------------|-----------|---------|----------------------|----------------------|
| Healthcare Professional | | | | | |
| Family member (spouse, parents, siblings, etc.) | | | | | |
| Neighbors/friends | | | | | |
| Peers | | | | | |
| Members of your rehab team | | | | | |

F. SELF-ADVOCACY

22. How strongly do you agree or disagree with the following statement?

| | | | | |
|---|--------------------------------|-------------------------------|-----------------------------|--------------------------------------|
| I am able to speak up for myself and ask for what I need (e.g. asking for funding, therapy, home care, home renovation/equipment) | | | | |
| <input type="radio"/> Strongly disagree | <input type="radio"/> Disagree | <input type="radio"/> Neutral | <input type="radio"/> Agree | <input type="radio"/> Strongly agree |

2. If you are able to speak up for yourself and ask for what you need, who are you asking for more funding or resources? (check all that apply)

- Insurance companies
- Workers' Compensation/Workplace Safety and Insurance Board
- Family member
- Service hubs
- Public healthcare system
- Not Applicable
- Other: _____

Figure 3 Continued

feasibility issues and challenges included: (1) the impact of cognitive and motor deficits on the ability to self-administer the tool; (2) inability to understand certain aspects of the tool (i.e. clarifications needed on specific language [e.g. emotional management]); and (3) additional time taken by patients to discuss the responses in depth.

Discussion

Self-management is a critical skill for enabling persons with SCI/D to maintain their health and wellbeing long-term in the community. Despite the growing awareness of self-management practices within Canada,³² these practices are inconsistently applied across tertiary rehabilitation hospitals. To help

SCI Self-Management Evaluation Tool

3. Have you ordered or purchased supplies/equipment yourself for any of the following? (check all that apply)

- Bladder management (i.e. pads, catheters, etc.)
- Mobility (i.e. wheelchairs, walker, canes, braces, etc.)
- Sleeping (i.e. special mattress, bed, attachments, etc.)
- Dressing (i.e. pullers, reachers, buttons, etc.)
- Toileting (i.e. raised toilet seat, commode chair, etc.)
- Bathing (i.e. tubseat, transfer seat, etc.)
- Meal prep (i.e. utensils, openers, etc.)
- Driving (i.e. vehicle modification)
- Home safety (i.e. ramps, railings, etc.)
- Pressure relief (i.e. cushions, mattress, etc.)
- Other: _____

G. BARRIERS TO SELF-MANAGEMENT

4. Below are some possible things that might get in the way of yourself-management. Please select any that you are feeling or have gone through:

- I prefer to let others manage my care
- I feel I don't have enough medical knowledge
- I am overwhelmed by my injury
- Looking after my medical situation is not my responsibility
- looking after other areas of my life takes up most of my time
- My medical issue makes it difficult to remember and plan
- I'm too tired
- I don't think self-management will help my recovery and health
- Someone told me not to
- It is too expensive to manage my health
- I don't experience barriers
- Other: _____

5. Please explain how we could help you reach your primary self-management goal.

Figure 3 Continued

address this inequity, the SCI-High Self-Management Working Group selected and developed structure, process and outcome indicators intended to: (1) identify learning gaps and improve capacity among rehabilitation HCPs and peer mentors in self-management; (2) promote documentation and integration of self-management skill acquisition into the rehabilitation process; and (3) help individuals with SCI/D acquire the necessary skills to manage their health and daily activities toward successful community integration.

It is vital to recognize that in order to enhance self-efficacy and practice self-management, individuals with

SCI must first have appropriate knowledge and skills pertinent to managing their injury.^{17,69} The first step towards addressing this issue of enhancing self-management education and skills is enabling facilitated conversations regarding specific patient self-management priorities and learning needs. The selected process indicator will provide an opportunity for HCPs to assess and understand patients' individual self-management goals, barriers to self-management and level of confidence in carrying out self-management behaviors, in order to direct care accordingly. The patients' responses are intended to guide self-

Table 2 Self-management outcome measures.

| Measurement Tool | Scale | Test Description |
|---|--|---|
| The Barthel Index (BI) ⁴⁴ | Number of items = 10 Scores are obtained primarily from using direct observation | Measures of basic activities of daily living 10 domains: 1. Bathing 2. Grooming 3. Feeding 4. Dressing 5. Toilet use 6. Ascend/descend stairs 7. Bowel management 8. Bladder management 9. Bed/wheelchair transfer 10. Mobility (level surface). Item scores are summed to give a total score ranging from 0 to 100 (0: fully dependent; 100: fully independent). |
| Continuous Scale Physical Functional Performance (CS-PFP) ⁴⁵ | 16 Tasks: Tests are scored by time to completion and/or by weight carried or height reached. (Wheel chair users: WC-PFP) | Assesses a person's ability to perform a variety of functional activities by having them actually perform, and not simulate, those activities. Low difficulty 1. Carrying a weighted pot 2. Pouring water from a jug to a cup 3. Donning/removing a jacket 4. Placing and removing a sponge from a shelf 5. Moderate difficulty 6. Sweeping floor with broom and dustpan 7. Door pull 8. Transferring clothes from washer to dryer & dryer to basket 9. Making a bed 10. Vacuuming 11. Placing a strap over shoe 12. Picking up scarves from the floor 13. High difficulty 14. Carrying weighted bag up and down simulated bus stop 15. Sitting and standing up from floor 16. Climbing stairs 17. Carrying groceries 18. Six minute walk Raw scores are converted to percentage scores for each task: Adjusted score = [(observed score – lower limit)/(upper limit – lower limit)] * 100. The upper and lower limits used are from Cress et al, 1996 validation study and based on data from older adults, ages 65–85 years. The scores range from 0 to 100, with higher scores indicating better function. |
| Frenchay Activities Index (FAI) ⁴⁶ | Number of items = 13 Four items (washing up, washing clothes, driving a car/bus travel, and gainful work) are scored on a 2-point scale. The 9 other items are scored on a 3-point scale. | Assesses frequency of performing Instrumental Activities of Daily Living (IADL). Self-administered or interview format using a 2 and 3 point ordinal scale. Total score are derived by summing the score from each item and range from 0 (no activity) to 22 (most frequently doing the activities). http://www.rehabmeasures.org/PDF%20Library/Frenchay%20Activities%20Index.pdf |

Continued

Table 2 Continued

| Measurement Tool | Scale | Test Description |
|---|---|---|
| Functional Independence Measure (FIM) ⁴⁷ | Number of items = 18 (13 motor and 5 cognitive items), a Likert scale ranging from 1 (complete assistance needed) to 7 (completely independent) | Assesses the degree of independence in activities of daily living in six areas of function: self-care, mobility, sphincter control, locomotion, communication and social cognition. Total FIM scores range from 18 (totally dependent) to 126 (totally independent); motor scores range from 13 (total dependence) to 91 (total independence); and cognitive scores range from 5 (total dependence) to 35 (total independence). |
| Functional Independence Measure Self-Report (FIM-SR) ⁴⁸ | Number of items = 18 The 18 items are rated on a 1–7 scale where 1 = total assistance is needed and 7 = complete independence | Assesses the degree of independence in activities of daily living in six areas of function: self-care, mobility, sphincter control, locomotion, communication and social cognition. Self-report (Telephone Interview) Total FIM scores range from 18 (totally dependent) to 126 (totally independent); motor scores range from 13 (total dependence) to 91 (total independence); and cognitive scores range from 5 (total dependence) to 35 (total independence). |
| Health Education Impact Questionnaire (heiQ) ⁴⁹ | Number of items = 42 | An outcomes and evaluation measure for patient education and self-management interventions for people with chronic conditions. Eight independent dimensions are included: Positive and Active Engagement in Life (five items, Cronbach's alpha (a) = 0.86); Health Directed Behavior (four items, a = 0.80); Skill and Technique Acquisition (five items, a = 0.81); Constructive Attitudes and Approaches (five items, a = 0.81); Self-Monitoring and Insight (seven items, a = 0.70); Health Service Navigation (five items, a = 0.82); Social Integration and Support (five items, a = 0.86); and Emotional Wellbeing (six items, a = 0.89). The heiQ will provide valuable information to clinicians, researchers, policymakers and other stakeholders about the value of patient education programs in chronic disease management. |
| Klein-Bell Activities of Daily Living Scale (K-B Scale) ⁵⁰ | Number of items = 170 | Can be used with persons with or without disability Developed to measure basic activities of daily living (ADL) independence in both adults and children. Items are divided into 6 sub-dimensions: 1. Mobility 2. Emergency Communication 3. Dressing 4. Elimination 5. Bathing/Hygiene 6. Eating 7. Clinician administered (1–3 h) |
| Lawton Instrumental Activities of Daily Living scale (IADL) ⁵¹ | Number of items = 8 Responses range from 0 unable or partially able to 1 "able" | Developed to assess the complex activities of daily living (ADLs) for older adults living in the community. It assesses a person's ability to perform tasks such as using a telephone, doing laundry, and handling finances. Self-report or by interview. Individual items are summed to give a total score. |
| Moorong Self-Efficacy Scale (MSES) ⁵² | Number of Items = 16 Each item is scored on a 7-point scale from 1 (very uncertain) to 7 (very certain). | Measures an individual's confidence in performing functional, social, leisure & vocational activities post-SCI. The total scale score is obtained by calculating the sum of the individual scores with a range from 16 to 112 https://www.scireproject.com/outcome-measures-new/moorong-self-efficacy-scale-mses http://www.rehab.research.va.gov/jour/09/46/1/perry.html |

Continued

Table 2 Continued

| Measurement Tool | Scale | Test Description |
|---|--|--|
| Motivational Model of Pain Self-Management (MMPSM) ⁵³ | Number of items = 10 | MMPSM is a short tool to measure perceived importance of and self-efficacy relating to self-management behaviors. Perceived importance is assessed by using the mean of 3 of these items, based on a 0–10 numeric rating scale. For exercise, the items were as follows: (1) "To what extent do you believe that regular exercise is important for managing your health and pain problem?" (2) "To what extent have you experienced direct and immediate benefits of exercise (such as encouragement from someone important to you, or feeling better right after you exercise) in the past?" (3) "To what extent do you currently receive encouragement or other benefits when you exercise?" |
| Patient Activation Measure (PAM) ⁵⁴ | Number of Items = 13 A Likert-type agreement scale with four response options (1=strongly disagree, 4=strongly agree). | Individual's knowledge, skill and confidence in managing his or her own health care. The raw score is calculated by adding all of the responses to the questions and range from 13 to 52. The converted activation scores range from 0 to 100. Based on these activation scores, individuals are placed into one of four stages of progressive activation: believes active role is important (PAM score of ≤47.0), has the confidence and knowledge to take action (PAM score of 47.1–55.1), is taking action (PAM score of 55.2–67.0) and is able to stay the course under stress (PAM score of ≥67.1) |
| Pearlin-Schooler Mastery Scale (PMS) ⁵⁵ | Number of Items = 7 Five-point Likert scale about the extent to which they agree (5=strongly agree) or disagree (1=strongly disagree) with the various statements. | Measures global sense of personal control. A PMS score ranges from 7 to 35, with a higher score reflecting greater mastery. |
| Physical Activity Scale for Individuals with Physical Disabilities (PASIPD) ⁵⁶ | Number of items = 13 Individuals respond to 2 ordinally ranked responses. Frequency responses range from 1 (never) to 4 (often) while duration responses range from 1 (less than 1) hour to 4 (greater than 4 h). | Captures information about leisure, household, and work related physical activity over the preceding 7 days. Assesses 5 distinct dimensions of physical activity: 1. Home repair 2. Lawn and garden work 3. Housework 4. Vigorous sport and recreation, Moderate sport and recreation, 5. Occupation and transportation. The average hours per day for each item is multiplied by a metabolic equivalent (MET) value associated with the intensity of the activity and summing over items 2 through 13. Scores range from 0 (no activity) to > 100 METS hr/day (very high). |

Continued

Table 2 Continued

| Measurement Tool | Scale | Test Description |
|--|---|---|
| Quadriplegia Index of Function (QIF) ⁵⁷ | Number of items = 37 The functional performance (item 1–9) categories are scored on a 5-point scale from 0 (dependent) to 4 (independent). | For individuals with tetraplegia due to SCI (designed to assess the client's understanding of skin care, nutrition, equipment, medications, and infections) Clinician-administered Assesses 10 ADLs: <ol style="list-style-type: none"> 1. Transfers 2. Grooming 3. Bathing 4. Feeding 5. Dressing 6. Wheelchair mobility 7. Bed activities 8. Bowel program 9. Bladder program 10. Understanding of personal care (is a questionnaire designed to assess the client's understanding of Skin care, nutrition, equipment, medications and infections) 11. The functional performance (item 1–9) categories are scored on a 5 point scale from 0 (dependent) to 4 (independent). Each category of functional performance is calculated according to weighted scores: <ul style="list-style-type: none"> • Functional performance categories: /180 • Understanding of personal care: /20 Total score of 200 can be divided by 2 to yield a score out of 100. |
| Quadriplegia Index of Function Short Form (QIF-SF) ⁵⁸ | Number of items = 6 | Developed to provide a sensitive global functional scale for measuring gains in individuals with tetraplegia during rehabilitation Clinician-administered; interview format Items include: wash/dry hair, turn supine to side in bed, lower extremity dressing, open carton/jar, transfer from bed to wheelchair and lock wheelchair. These items were selected from five of the functional performance categories of self-care and mobility on the QIF in order to reduce item redundancies of the original 37-item version. Scores from the 6 items are summed and scores range from 0 to 24. |
| Self-Care Assessment Tool (SCAT) ⁵⁹ | Number of items = 81 (41 cognitive and 40functional) | Assess cognitive and self-care skills required by individuals with an SCI below C7 to perform self-care. Specifically for the SCI patient Eight self-care areas: <ol style="list-style-type: none"> 1. Bathing/grooming 2. Nutritional management 3. Medications 4. Mobility/transfers/safety 5. Skin management 6. Bladder management 7. Bowel management. Interviewer-administered test A cognitive and a functional subscale score can be calculated as well as an overall score, although no details are provided on how to calculate the scores. |

Continued

Table 2 Continued

| Measurement Tool | Scale | Test Description |
|--|---|--|
| Spinal Cord Injury Functional Index (SCI-FI) ⁶⁰ | The SCI-FI calibrated item banks include: basic mobility (54 items), self-care (90 items), fine motor function (36 items), ambulation (39 items) and wheelchair mobility (56 items) | Assess five functional domains: Basic mobility (Bed mobility, transfers, sitting, standing), self-care (Washing, dressing, grooming, eating), fine motor function (Manipulating objects), ambulation (Walking (vary speed, time, conditions), standing, stepping, and stopping, running and stairs) and wheelchair mobility (Stopping and starting in a manual and/or power wheelchair; moving in a MWC and/or PWC over a variety of surfaces, ramps and curbs). https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3910090/ https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5020585/ |
| Spinal Cord Injury Lifestyle Scale (SCILS) ⁶¹ | Number of items = 25 The frequency with which each behavior has been performed over the past 3 months is rated using an ordinal scale where 4=almost always, 3=frequently, 2=sometimes, 1=rarely and 0=never. One item (genitourinary) is reverse scored. | Measures the frequency of health-related behavior performance in individuals with SCI Designed to enable examination of the effectiveness of clinical and educational efforts for health maintenance and prevention of secondary impairments Self-report The 5 subscales include: 1. Cardiovascular 2. Genitourinary 3. Neuromuscular 4. Skin 5. Psychosocial A score is generated for each subscale by totaling scores of each item in the subscale. A total score ranging from 0–100 is calculated by summing the 5 subscale scores. |
| Spinal Cord Independence Measure (SCIM) ⁶² | Number of items = 19 | Disability scale developed to specifically address the ability of SCI patients to perform basic activities of daily living independently. Three versions of the SCIM (I-III) have been consecutively developed and assess three areas: 1. self-care (feeding, grooming, bathing, and dressing) 2. Respiration and sphincter management 3. Mobility (bed and transfers and indoor/outdoor) The item scores are weighted related to the assumed clinical relevance. Scores are derived by adding up the items producing a total score (0–100) and/or subscale scores (self-care: 0–20; respiration and sphincter management: 0–40; mobility 0–40). |
| Self-Reported Functional Measure (SRFM) ⁶³ | Number of items = 13 The 4 – point scale is as follows: 4 = no extra time or help, 3 = extra time or special tool, 2 =some help, and 1= total help or never do. | Self-report or interview; can be administered either in person or by mail. Questionnaire has four level response categories to 13 items of basic ADL and 5 items of instrumental (No cognitive and communications domains ADL) Questions are asked based on an average day and the individual's usual way of doing the activity. Total scores (13–52) are derived by summing the scores from each question. |

Continued

Table 2 Continued

| Measurement Tool | Scale | Test Description |
|---|--------------|---|
| Self-management screening questionnaire (SeMaS) ⁶⁴ | 27 questions | The SeMaS is a short validated tool that can signal potential barriers for self-management that need to be addressed in the dialogue with the patient. The questionnaire comprises of 27 questions that were mainly derived from validated questionnaires. Characteristics of the tool include: self-efficacy, locus of control, depression, anxiety, coping, social support, and perceived burden of disease. As such it can be used to facilitate personalized counselling and support to enhance self-management in patients with chronic conditions in primary care. SeMaS is a short validated tool that can signal potential barriers for self-management that need to be addressed in the dialogue with the patient. As such it can be used to facilitate personalized counselling and support to enhance self-management in patients with chronic conditions in primary care. |

Table 3 Self-management outcome indicator tool- modified Health Education Impact Questionnaire (m-heiQ).

Please indicate how strongly you agree or disagree with the following statements by checking the response that best describes you now.

| | | Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree |
|---------------------------------|--|-------------------|----------|---------|-------|----------------|
| Skill and Technique Acquisition | 1. When I have symptoms, I have the skills that help me cope | | | | | |
| | 2. I am very good at using aids and devices to make my life easier | | | | | |
| | 3. I have effective skills that help me handle stress | | | | | |
| | 4. I have a very good idea of how to manage my health problems | | | | | |
| | 5. I have effective ways to prevent my symptoms from limiting what I can do in my life | | | | | |
| Self-Monitoring and Insight | 6. With my health in mind, I have realistic expectations of what I can and cannot do | | | | | |
| | 7. As well as seeing my doctor, I regularly monitor changes in my health | | | | | |
| | 8. I know what things can trigger my health problems and make them worse | | | | | |
| | 9. When I have health problems I have a clear understanding of what I need to control them | | | | | |
| | 10. I have a very good understanding of when and why I am supposed to take my medication | | | | | |
| | 11. I carefully watch my health and what is necessary to keep as healthy as possible | | | | | |
| | 12. I know when my lifestyle is creating health problems for me | | | | | |

Note: The Health Education Impact Questionnaire © Copyright 2015 Deakin University. Authors: RH Osborne, K Whitfield, GR Elsworth.

management education provided by a rehabilitation professional by focusing on what they report are most important to them. Targeted and personalized management along with patient-mediated strategies

are critical in implementing a self-management intervention (*i.e.* interventions enhancing self-management education and knowledge).⁷⁰ This should begin in the inpatient setting prior to discharge from rehabilitation

and carry over as they reintegrate into the community.³²

Although the importance of educating individuals with SCI/D and their family members about self-management is recognized, including how to prevent SHCs, there is a shortage of qualified HCPs to provide such self-management education.⁷¹ Due to the relatively low prevalence of individuals with SCI/D, only a few primary HCPs have individuals with SCI/D in their practice.⁷² Thus, the majority of the primary care providers do not often have much opportunity to obtain adequate training and sufficient knowledge and skills to provide self-management education to their patients.⁷³ To assist the various disciplines of HCPs in the rehabilitation setting in providing self-management education and helping the individuals with SCI/D to manage their health and daily activities toward successful community integration, the Self-Management Working Group felt there should be an initiative to enhance staff capacity- in other words, continuing education hours toward developing/enhancing their training and skills specific to self-management. A first step to enhancing capacity in this domain of care across Canada is to determine what extent staff training incorporates the best methods to facilitate self-management skill development among individuals with SCI/D, and whether these processes are conducted and/or documented appropriately during inpatient rehabilitation. Doing so will provide important knowledge about the state of self-management across Canada in SCI/D rehabilitation where there is an increasing need to ensure equity of access to clinical care across the country.³⁸ Further, it will help build capacity in HCPs working in rehabilitation, as well as foster a culture conducive to self-management across the continuum of care. The indicators developed by the Working Group are projected to create a new minimum threshold of self-management knowledge and skills among HCPs to identify and address the self-management needs of individuals with SCI/D and their family members in the first 18 months post inpatient rehabilitation admission.

One challenge is that some healthcare providers at tertiary rehabilitation centers have adequate self-management education and training, but there may not be any appropriate documentation of their practice. There is an increasing need to ensure equity of access to clinical care nationally to optimize the quality of care by standardizing the timing and format of self-management assessments during inpatient rehabilitation, as well as in the community using valid and reliable assessment tools. Therefore, our developed process indicator aims to address this gap by ensuring

appropriate documentation of the facilitated conversations with patients regarding specific self-management goals.

A few potential barriers with the proposed indicators should be considered. First, self-management is a complex and challenging construct to measure in a condensed timeframe. For example, each individual with SCI/D goes through a unique journey (based on specific injury conditions, age, sex, etc.), and self-management education and skill needs will be continuously evolving depending on the timing and setting across the care trajectory and the individuals psychosocial and environmental context. Thus, the assessment of self-management needs and accompanying strategies during these time points in an individual's journey are unique to the individual and vary in complexity. Furthermore, the Project Leaders agreed that the indicators should be concise and feasible to implement (*i.e.* within 10 min), which may have compromised a comprehensive assessment. In addition, these indicators were designed for use by any health care professional, not just someone with a psychology background, therefore, they are grounded in skill acquisition, not theory. Although this approach allows for universal usability, it does not deter a psychologist/social worker from conducting an intimate comprehensive assessment in addition to the indicators and related practices. To add, readiness to receive self-management education is difficult to assess due to the fact that individuals with SCI/D also evolve in their readiness to gain new information related to managing their health and integrating back into the community post-SCI. At this stage, the Working Group is aiming to identify tools to assess "readiness" (to receive self-management education). Regardless, these initial indicators were intentionally developed to be feasible at critical SCI rehabilitation transition points, which can help to set the stage for nationwide validation and benchmarking to advance access to appropriate care.

Conclusion

Successful implementation of the selected structure, process and outcome indicators and related best practices for Self-Management will simultaneously promote self-management education and skill acquisition as a rehabilitation priority and empower individuals with SCI/D to manage their health and daily activities towards successful community integration. Moreover, self-management interventions are not well-developed and there is a pressing need for directed research to bolster evidence underlying the service delivery gaps to better integrate self-management

education into SCI/D rehabilitation care process. More importantly, providing self-management education when the individual is ready to engage in this learning as soon after injury as possible will likely lead to a decrease in the onset of SHCs as individuals with SCI/D will be better equipped to self-manage their health in the community, and in return, reduce the burden on the Canadian healthcare system.

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ORCID

Gaya Jeyathevan  <http://orcid.org/0000-0001-5525-3214>

Susan B. Jaglal  <http://orcid.org/0000-0002-2930-1443>

Sander L. Hitzig  <http://orcid.org/0000-0002-9139-9250>

Gary Linassi  <http://orcid.org/0000-0003-3343-4262>

Sandra Mills  <http://orcid.org/0000-0002-8525-555X>

Vanessa K. Noonan  <http://orcid.org/0000-0003-3226-9218>

Teren Clarke  <http://orcid.org/0000-0002-2598-6326>

Dalton Wolfe  <http://orcid.org/0000-0002-8680-7360>

Mark Bayley  <http://orcid.org/0000-0001-7860-9463>

Lubna Aslam  <http://orcid.org/0000-0002-6612-0289>

Farnoosh Farahani  <http://orcid.org/0000-0002-3937-7708>

S. Mohammad Alavinia  <http://orcid.org/0000-0002-5503-9362>

Maryam Omidvar  <http://orcid.org/0000-0003-2415-8921>

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

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