Research Article

Development of Wheeled Mobility indicators to advance the quality of spinal cord injury rehabilitation: SCI-High Project

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Background: Wheeled mobility is critical for individuals with Spinal Cord Injury or Disease (SCI/D) related paralysis. The World Health Organization (WHO) developed guidelines highlighting eight steps in wheelchair service delivery: (1) referral and appointment; (2) assessment; (3) prescription; (4) funding and ordering; (5) product preparation; (6) fitting; (7) user training; and, (8) follow-up maintenance/repairs. This article describes the processes used to develop structure, process and outcome indicators that reflect the WHO guidelines within the Domain of Wheeled Mobility rehabilitation for Canadians.

Methods: Wheeled mobility experts within the SCI-High Project Team used the WHO guideline to inform the Construct refinement and development of a Driver diagram. Following seven meetings, the Driver diagram and review of outcome measures and literature synthesis regarding wheelchair service delivery informed indicator selection and group consensus.

Results: The structure indicator examines the proportion of SCI/D service providers within a rehabilitation program who have specialized wheelchair training to ensure prescription, preparation, fitting, and maintenance quality. The process indicator evaluates the average number of hours of wheelchair service delivery provided per patient during rehabilitation. The intermediary outcome indicator (rehabilitation discharge), is a target capacity score on the Wheelchair Skills Test Questionnaire (WST-Q). The final outcome indicators (at 18 months post rehabilitation admission) are the Life Space Assessment (LSA) and the Wheelchair Use Confidence Scale (WheelCon) short form mean scores.

Conclusion: Routine implementation of the selected Wheeled Mobility structure, process and outcome indicators should measurably advance care within the Wheeled Mobility Domain for Canadians living with SCI/D by 2020.

Keywords: Spinal cord injuries, Healthcare quality indicator, Rehabilitation, Wheelchair, Wheeled mobility

Introduction

Over 95% of individuals with motor complete spinal cord injury or disease (SCI/D) 1 and about 40% of those with incomplete injuries (AIS C) will not return to walking. 2 With regard to walking function, a
number of recent articles compared the recovery of ambulation in individuals with traumatic and non-traumatic SCIs and found that the two populations achieve comparable walking capacity, with an overall percentage varying from 35 to 49. The inability to regain independence in walking is often due to trunk instability, lower extremity weakness, severe lower extremity spasticity, inadequate cardiorespiratory function or poor dynamic balance alone or in combination, necessitating a wheelchair for household and community mobility. Even individuals fortunate enough to return to walking short distances at home, may require a manual or power wheelchair for community mobility.

Wheelchairs, both manual and power, are the most frequently used devices for community mobility among individuals with SCI/D. Wheelchairs have positive effects on the community mobility and social participation of users. Further, wheelchairs can reduce caregiver burden. However, wheeled mobility is not without problems; wheelchair users experience difficulties propelling their device secondary to their motor, cognitive, visual and perceptual impairments, experience overuse injuries, report difficulties transporting their wheelchairs in vehicles, and challenges in obtaining funding or locating technicians for wheelchair service and repair.

Beyond these concerns, many environments are inaccessible and require advanced wheelchair skills to maneuver safely. Safety is a concern with 5–18% of community wheelchair users reporting wheelchair-related injuries each year. Additionally, inappropriate prescription, inadequate fitting and insufficient wheelchair mobility skills training are all associated with severe health conditions including tissue injury, secondary upper extremity and trunk musculoskeletal overuse injuries, carpal tunnel syndrome, and nociceptive pain. Further, prolonged non-active sitting time in a wheelchair contributes to increased cardiometabolic risk.

The World Health Organization (WHO) has advocated an eight-step service delivery process that has been widely endorsed by rehabilitation professionals. The steps are: (1) referral and appointment, (2) assessment, (3) prescription, (4) funding and ordering, (5) product preparation, (6) fitting, (7) user training, and (8) follow-up, maintenance, and repairs. There is growing research evidence to support the safety and effectiveness of some of the individual WHO steps and growing evidence to support the overall process.

Once the wheelchair has been prepared, wheelchair mobility skills training can improve an individual’s health and independence. However, wheelchair skills training often competes with other priorities during inpatient rehabilitation, and skills training may be inadequately addressed with growing health system pressures to reduce inpatient rehabilitation length of stay. Teeter et al. reported that, during the initial SCI rehabilitation stay, a mere average of 4.2 h/patient was spent developing manual wheelchair mobility skills. Best et al. reported that therapists in Canadian rehabilitation centers only carried out ~1–4 h of training, ranging from none (~18%) to 10 h or more. About 69% of rehab centers offered advanced wheelchair skills training sometimes; whereas, only 12% routinely offered wheelchair skills training. This data suggests an insufficient amount of time is spent on wheelchair skills training. In some rehabilitation environments, the caseload of busy clinicians reduces the feasibility of wheelchair mobility skills training interventions by clinicians. Thus, peer-led training, therapist-monitored home training, and physical activity counselling programs have been proposed as alternative interventions to augment community integration.

Although there are evidence-based interventions to promote optimal wheeled mobility outcomes, there is limited data about how the Canadian SCI/D rehabilitation system performs. Audit of quality indicators is one of the proposed strategies to promote best-practice implementation. Quality indicators are widely used to identify trends, inform priority setting and policy formulation, and monitor rehabilitation programs and care processes. Indicators can further inform comparisons across different health care settings and ensure continuous quality improvement (i.e., benchmarking). Indicators can measure the structure, process, or outcome of health care services and their evaluation can facilitate the sustainability of high-quality, evidence-based health care delivery systems. Structure indicators are defined by the properties of the setting in which health care occurs. Process indicators describe what is actually done in giving and receiving care, while an outcome indicator reflects the patient’s mortality, morbidity, health status, health-related quality of life or satisfaction with life because of the context of the care provided.

The SCI Rehabilitation Care High Performance Indicators (or “SCI-High”) Project endeavors to advance SCI/D rehabilitation care in Canada by 2020 through the development/selection, implementation, and evaluation of indicators of quality care for 11 Domains of rehabilitation care for individuals living with SCI/D. The SCI-High Project Team is comprised of relevant stakeholders including health care providers, scientists, administrators, leaders, policymakers,
consumers, and representatives from Accreditation Canada (https://accreditation.ca), Canadian Spinal Research Organization (www.csr0.com), SCI Canada (https://sci-can.ca), Ontario Neurotrauma Foundation (www.onf.org), and the Rick Hansen Institute (www.rickhanseninstitute.org). Further information about the SCI-High project can be found at www.sci-high.ca.

To ensure feasibility of indicator measurement, each of the 11 Domain Working Groups including the Wheeled Mobility Working Group was asked to identify and develop at least one structure, one process and one outcome indicator to evaluate the quality of SCI/D rehabilitation care. This manuscript describes the Wheeled Mobility Working Group’s processes and rationale for selection of the initial framework of Domain-specific indicators for adults with SCI/D admitted to tertiary SCI/D rehabilitation programs in Canada during the time-period from rehabilitation admission to 18 months thereafter.

**Methods**

The overall SCI-High Project methods and process for identifying Wheeled Mobility as a priority Domain for SCI/D rehabilitation care are described in related manuscripts in this issue respectively. In addition to the SCI-High Project Team, an External Advisory Committee, and a National Data Strategy Committee supported the global project goals and provided oversight regarding the context for implementing all of the planned indicators. The SCI-High Project Team stipulated that the indicators must be relevant, concise (10 min or less to implement), feasible, and aligned across the structure, process and outcome indicators to measure critical information that would drive advances in quality care within each Domain of SCI/D rehabilitation. The indicators could be derived from established or new measurement tools (i.e. questionnaires, data collection sheets, laboratory exams, and medical record data), depending on the requirements of a given indicator and the state of the relevant literature.

The approach to developing the Wheeled Mobility Domain structure, process and outcome indicators followed a modified, but substantially similar, approach to that described by Mainz et al., which included the following processes: (a) formation and organization of National and Local Working Groups; (b) defining and refining the key Domain Construct and specific Aim; (c) providing an overview/summary of existing evidence and practice; (d) developing and interpreting a Driver diagram that conveniently displays factors important for optimizing outcomes in that Domain; (e) selecting indicators; and, (f) pilot testing and refinement of the Domain-specific structure, process and outcome indicators. Throughout these processes, a discussion facilitated by the SCI-High Project Team co-leader (MB) occurred amongst the Domain-specific Working Group members to utilize relevant expertise on the topic, while ensuring the broader goals of the SCI-High Project were aligned across the other 10 Domain Working Groups (as appropriate).

**Wheeled Mobility Working Group**

Experts in wheeled mobility and relevant stakeholders were invited to participate in the SCI-High Project as members of the Domain Working Group based on their practical or empirical knowledge of SCI/D rehabilitation, wheeled mobility, and health services. The group was composed of two clinician scientists (MD), two occupational therapists, two physical therapists, and two scientists (PhD), and the SCI-High Project Team. The Working Group met nine times via conference call between October 2016 and Mar 2019, totaling nine hours of discussion. In addition, individual members of the Working Group completed their own independent reviews of the prepared materials, or shared resources and or practice standards with one another via email, or conducted independent evaluations of the proposed indicators outside of the scheduled meetings. The Working Group meetings were designed to: (1) review the key constructs related to wheeled mobility; (2) develop an evidence-informed Driver diagram and review the available outcome indicators; and (3) narrow the multiple options to three indicators of the quality of wheelchair service delivery from the time of admission to a tertiary rehabilitation facility to 18 months post-admission. Initially, the Working Group discussed relevant scientific evidence and used expert consensus to develop a Construct definition for wheeled mobility to define the scope and goals of care within the Wheeled Mobility Domain.

The process for structure, process and outcome indicator selection (outlined below) commenced with a literature search and was followed by development of a Driver diagram that facilitated consideration of all factors affecting independence in wheeled mobility. A Driver diagram is a visual display of a high-level quality improvement goal, and a set of underpinning factors/goals. The tool helped to organize change concepts as the Working Group discerned “what changes can we make, that will result in goal attainment”.

**Literature search**

A comprehensive literature search on MEDLINE, PubMed and Google Scholar using combinations of
the search terms “wheeled mobility” and “spinal cord injury” was conducted by two members of the SCI-High Project Team independently (MA, MO) up to August 2018. The search identified 625 initial articles following duplicate removal. Eleven non-English manuscripts and manuscripts unrelated to the Domain construct were excluded. Twenty-two outcome measures related to the Wheeled Mobility Domain construct and factors that influence service provision in SCI/D rehabilitation were selected for consideration for process and/or outcome indicator development (See Table 1). The clinimetric properties of the tools and feasibility for clinical implementation were key considerations.

**Driver diagram**

Creation of a Driver diagram enables a root cause analysis of a problem or situation using quality improvement methodology. Following review of the literature-search results, the Wheeled Mobility Working Group elected to develop the diagram consistent with their Construct by including the eight key steps reflected in the WHO guideline for wheelchair service delivery. These classifications were different from a traditional Driver diagrams used by the other Domain Working Groups within the SCI-High Project; however, incorporation of the WHO steps in the Driver diagram allowed the Working Group to identify key factors to advance wheeled mobility outcomes (Fig. 1). The reader will note that wheelchairs skills acquisition appears in steps six, seven and eight of the WHO wheelchair provision guideline, and the associated arms within the Driver diagram and their relative importance are reflected throughout the indicator development process. A group survey was initially completed to prioritize which three steps of the WHO guideline most contributed to Wheeled Mobility and are essential to achieving optimal outcomes. Following the survey, Working Group consensus was achieved by focusing on assessment, training, and fitting as the top three steps upon which to focus indicator development.

**Selection of indicators**

The structure, process and outcome indicators were derived from evaluation of the WHO guidelines, Domain Working Group discussions, clinical expertise, focus group validation and existing literature. Using a consensus process, fundamental and strategically important outcomes were selected, as they were deemed feasible to collect in a clinical setting and likely to advance practice related to provision of wheelchair service delivery and wheelchair skill development.

**Focus group activities**

Local pilot validation of elements related to the evaluation of the proposed indicators was done at the Toronto Rehabilitation Institute. Thirteen occupational therapists and seven occupational therapy assistants reviewed and discussed the proposed staff tool for structure indicator as well as the wheeled mobility service delivery steps for process indicator for face validity during two one-hour meetings. The staff provided individual feedback to the SCI-High Project team related to current training and education opportunities, as well as feasibility of data collection after implementing the proposed process indicator among a few patients. This focus group feedback was used to specify the best mechanisms for timely and accurate collection of process indicator data during day-to-day practice by linking data collection to site-specific workflow tools.

**Results**

**Construct definition**

The Wheeled Mobility Domain Working Group developed the following Construct definition:

Wheeled mobility refers to the skilled use of any personal device with wheels including power wheelchairs, and manual wheelchairs (with arm
or foot propulsion), by individuals with physical impairments such as spinal cord injury (SCI/D), to allow full participation in daily life.

The Aim was, “to maximize community wheelchair mobility through the implementation of routine standardized wheelchair mobility assessments”.

Indicator development

As there is no current consensus derived “gold standard” certification for specialized wheelchair mobility skills training in Canada, a tool was developed to capture relevant international training and certification data on an annual basis. The process was intended to allow the Working Group to define the expertise and training benchmarks on a go-forward basis. Table 2 displays the training and certification variables needed to inform the structure indicator. These aforementioned staff training and certification variables were incorporated into a questionnaire for administration of the structure indicator (See Supplemental Material 1). At the time of indicator development, the Working Group anticipated that an affirmative response to category 2 certification and significant training within Table 2, would be deemed “optimal certification” for members of an inter-professional seating team.

The Wheeled Mobility Domain structure, process and outcome indicators are shown in Table 3 (The tools specified in the indicator table may be found in Supplemental Materials 2, 3 and 4). A key challenge for regulated health care professionals working with patients experiencing neurological and functional recovery is to decide at what time point it is appropriate to collect walking indicators versus wheeled mobility indicators or both for patients transitioning from wheeled mobility to walking. Figure 2 provides the clinician with a decision tool based on the Standing and Walking Assessment Tool (see Walking Domain manuscript in this issue) to decipher which set of indicators are most appropriate to collect.

The process indicator (i.e. hours of wheeled mobility service delivery) will be collected by treating regulated healthcare professionals who will record the time involved in each of the specified wheelchair service delivery activities outlined in Table 4 each day during tertiary inpatient rehabilitation. The process indicator will be measured by summing the time spent in all activities related to wheelchair skill development during the individual’s rehabilitation admission.

The intermediary outcome indicator (WST-Q) was selected for the wheelchair skills assessments of both manual and power wheelchair users at rehab discharge. This tool is a subjective self-report measure requiring 10 min to complete and captures information on both capacity (what the individual can do) and performance (what the individual does do).
The outcome indicators (LSA and WheelCon) were selected as they can be administered by self-report (in person or remotely by phone or online) at 18 months post-rehabilitation admission. The WheelCon measures wheelchair confidence in 6 conceptual areas: (1) negotiating the physical environment; (2) activities performed in the wheelchair; (3) knowledge and problem solving; (4) advocacy; (5) managing social situations;
managing emotions which considers the individual’s social and environmental contexts of the participation construct within the International Classification of Functioning, Disability and Health (ICF). We anticipate that the WheelCon data will provide insight into the long-term performance of wheelchair users in the community nationally.

Discussion
This is the first effort to identify quality indicators for optimal SCI/D rehabilitation in the Domain of Wheeled Mobility. Wheelchair service delivery is a complex process with many steps that challenged the Wheeled Mobility Working Group’s approach to identifying a minimal set of one structure, process or outcome indicator for the entire Domain. Given the complexity of the wheelchair service delivery process, and the multiple steps necessary to achieve community mobility, the Working Group chose to introduce a single structure and process indicator as well as one intermediary and two outcome indicators. The outcome indicators evaluate the individual’s wheelchair skills at rehabilitation discharge, and describe their community participation and mobility confidence at 18 months post rehabilitation admission. When selecting indicators of quality care, the context and setting in which indicators are deployed are important considerations. This choice of indicators was predicated upon

Figure 2 Walking and Wheeled Mobility Domain indicator decision tree. Appropriate indicator data collection is based on the patient’s stage of standing and walking recovery ascertained using the Canadian SCI Standing and Walking Assessment Tool. The Figure is intended to help clinicians decide when it is appropriate or not to collect Wheeled Mobility or Walking indicators, or both, based on the individual’s stage of standing and walking recovery. WST-Q: Wheelchair Skills Test Questionnaire; mTUG: modified Timed Up and Go; 10 MWT: 10 Meter Walk Test; LSA: Life-Space Assessment; WheelCon: Wheelchair UseConfidence Scale; SCIM III: The Spinal Cord Independence Measure version III. *Canadian Spinal Cord Injury Standing and Walking Assessment Tool.

(6) managing emotions which considers the individual’s social and environmental contexts of the participation construct within the International Classification of Functioning, Disability and Health (ICF). We anticipate that the WheelCon data will provide insight into the long-term performance of wheelchair users in the community nationally.
the timing for wheelchair delivery in provinces across Canada.

The Working Group chose to embed the WHO guidelines for wheelchair provision into the Driver diagram and carefully selected outcomes that were feasible for clinical implementation, while assuring measurement of an appropriate underlying construct and selection of indicators with prior clinometric evaluation within the SCI/D population.

The first driver of Wheeled Mobility identified was access to a specialized team with relevant training and expertise. A specialized team was deemed necessary, to ensure the key steps in the WHO wheelchair service delivery process would be efficiently and appropriately, completed. This led to selection of the structure indicator to evaluate whether the current wheeled mobility teams across Canada include regulated healthcare professionals with specific prior training, certification and experience; however, no single instrument existed. The Working Group acknowledged several existing training programs (International Society of Wheelchair Professionals (ISWP) Basic Test, Rehabilitation Engineering Society of North America (RESNA) – Assistive Technology Professional (ATP) Certification and (RESNA) – Seating and Mobility Specialist (SMS) Certification). Rather than selecting one certification program over another, the Working Group acknowledged that any of these aforementioned certifications were substantive indication of the necessary expertise. Following large-scale implementation of this structure indicator, benchmarks for training and certification, will be proposed by the SCI-High Project Team.

The second driver of Wheeled Mobility identified was the total number of hours of wheelchair service provision provided to each individual patient during rehabilitation. Patient training and education are one of the key steps in wheelchair service delivery. Benchmarking the number of hours that each patient receives related to wheelchair skills training as well as all other essential steps in the provision of a wheelchair as outlined by the WHO guideline, could help to ensure all patients get at least adequate training and appropriate equipment to maximize their mobility and functional abilities. This process indicator will report on the time allocation and clinical priorities related to the steps defined in the WHO guideline, producing background information to support the results from the outcome indicators related to wheeled mobility skills and effectiveness. Previous reports showed that the appropriate implementation (i.e. appropriate number of hours) of the WHO 8-steps program improved wheelchair user’s satisfaction and quality of life, aligning with the Working Groups goals.

There is evidence that wheelchair skills capacity is associated with measures of community participation. The Wheelchair Skills Training Program (WSTP) is a well-established program for which the safety and effectiveness has been documented.16,18 On March 20, 2019, the dynamic link on the Wheelchair Skills Program website https://wheelchairskillprogram.ca/en/publications-impact/ identified 43 peer-reviewed papers about the Wheelchair Skills Training Program detailing 15 randomized clinical trials and two systematic reviews and meta-analyses to support the importance of skills training highlighted in the Driver diagram. The Wheelchair Skills Test (WST) and the Questionnaire version (WST-Q) have been well studied from the perspective of their clinimetric properties, and are widely used as outcome measures in the wheelchair literature. On March 20, 2019, the dynamic link on the Wheelchair Skills Program website showed 73 peer-reviewed papers regarding use of these measures, providing substantial impetus for routine implementation in routine clinical practice. Selection of the WST-Q capacity measure as the intermediary outcome should ensure that the wheelchair
mobility skills training was effective. The WST-Q is sufficiently self-evident to be self-administered by patients and/or their caregivers. For therapists, all of the materials (WSP Manual and Forms) are available freely online. Thus, there are no significant challenges to WST-Q implementation. The Working Group envisioned increased uptake and use of the WST and WST-Q with indicator deployment, although other wheelchair mobility skills training approaches can also be considered to maximize community integration, such as peer-led wheelchair training, therapist-monitored home training, and physical activity counseling. However, further multi-site deployment and evaluation of other forms of wheelchair skills training is needed to demonstrate their effectiveness in clinical settings. The ultimate goal of Wheeled Mobility skills training is to allow individuals with SCI/D to participate fully in all societal roles.

The SCI-High Project Team dictated that the selected indicators should ideally be valid, reliable and feasible to implement within the context of an outpatient follow-up visit to a rehabilitation program, anticipating that administration of the 11 Domain indicators would take about an hour to complete 18 months post rehabilitation admission. Within this context, and given the logistical constraints, the Life Space Assessment (LSA) and the Wheelchair Use Confidence (Wheel-Con) Scale measures were selected for their relevance to wheeled mobility within the community and ease of administration in a variety of settings. The developed indicators are intended to be used as a barometer of health system performance and to understand how changes in wheeled mobility will influence the lived experiences of individuals with SCI/D.

**Limitations**

To ensure feasibility, this process engaged a limited number of stakeholders; however, there was a balance of clinicians with recognized international experts. The questionnaire to identify expertise in wheelchair service provision, was piloted, but requires further refinement and application of benchmarks, to realize their intent. During the course of the Working Group’s activities, funding for wheelchair service provision was changing in some provinces across Canada, and the implications for individuals based on income were discussed, but not addressed, during the indicator development process. Feasibility, timing of data collection, and the number of indicators may also be limiting factors. Feasibility will be improved over time when the indicator data collection becomes a natural process within the provision of SCI/D rehabilitation care, which is one of the long-term goals of the SCI-High project. Keeping the indicators meaningful but at the same time short and straightforward can contribute to optimizing clinical implementation and participant retention over time.

**Conclusions**

In summary, successful implementation of the developed structure, process and outcome indicators has the potential to characterize the current state of wheeled mobility staff expertise and skill training for individuals with SCI/D during the first 18 months following rehabilitation admission. These indicators will address key elements by: (1) ensuring the availability of specialized professionals, who have the skills to complete the process of wheelchair service provision; (2) identifying the total hours of wheelchair mobility skills training provided during tertiary SCI/D rehabilitation; and, (3) measuring whether these service delivery processes, lead to meaningful degrees of confidence in wheelchair use, skill capacity, and community mobility. The implementation of these structure, process and outcome indicators will describe the current state of the SCI/D rehabilitation programs and will be crucial to providing equitable and optimal care related to the Wheeled Mobility Domain after SCI/D.

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