ORIGINAL ARTICLE

Spinal Cord Essentials: the development of an individualized, handout-based patient and family education initiative for people with spinal cord injury

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Study design: Mixed (environmental scan, qualitative and semiquantitative).

Objectives: To develop a customizable patient and family education resource for people with spinal cord injury (SCI).

Setting: SCI rehabilitation center (Canada).

Methods: An environmental scan was conducted and stakeholder input sought to generate a list of potential handouts and inform content development. Staff members were recruited to draft handouts, which were later edited and finalized by the project team. Hardcopies of handouts were placed in cabinets throughout the rehabilitation center. Staff members were also trained/coached to facilitate and promote usage; which was then tracked for 2 years.

Results: One hundred and fifty-six potential handouts were identified; 83 deemed high priority. Seventy-two handouts addressing patient organization, self-management and community integration were finalized for phase 1. At inpatient admission, patients receive a binder containing base materials. The binder is then customized and populated with pertinent handouts throughout the rehabilitation admission, and taken home at discharge for future reference. Handouts with the highest usage covered medical management (for example, bladder, bowel and pressure ulcers), mobility and activities of daily living. Handouts were also helpful for staff training and orientation, as well as increasing the confidence of staff providing education outside their immediate area of expertise.

Conclusion: Spinal Cord Essentials is a novel patient and family education initiative comprised of practical handouts that address many important aspects of SCI management. Handouts can be downloaded for free in four languages (English, French, Chinese and Farsi) at www.spinalcordessentials.ca. Additional handouts are planned for subsequent phases of the project.

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Keywords: spinal cord injuries; teaching materials; health education; health promotion

INTRODUCTION

Patient and family education is integral to spinal cord injury (SCI) rehabilitation. Information needs are particularly important for personal care, maximizing independence and preventing and managing secondary health complications;^{1–5} however, the psychological and physical effects of the injury can present challenges to learning readiness.^{5–7} Although the volume of information that patients are faced with during inpatient rehabilitation can be overwhelming,⁸ appropriate delivery of patient education is imperative to reduce and prevent secondary health complications.^{9–13}

Due to different learning styles, educational materials should be available in multiple formats and forums to ensure access to information when the need arises.⁷ Wolfe *et al.*⁸ recommended that the optimal delivery of information during inpatient rehabilitation is through ‘small chunks’ of information, such as brief handouts. The purpose of this manuscript is to (1) describe development and implementation and (2) increase awareness of Spinal Cord Essentials, a patient and family education initiative at the University Health Network—Toronto Rehabilitation Institute (UHN-TRI, Toronto, ON, Canada).

MATERIALS AND METHODS

Identification of content

Current educational materials were identified at the UHN-TRI and other select rehabilitation centers in Canada and the United States. Identified resources included seven books: *After and Beyond Spinal Cord Injury*,¹⁴ *Life After Spinal Cord Injury* books,^{15,16} *Craig Hospital SCI Handbook*,¹⁷ *Yes, You Can* 4th Edition,¹⁸ *Magee Rehabilitation SCI Patient-Family Teaching Manual*,¹⁹ and *Rehabilitation after a SCI: A Guide for You after SCI*.²⁰ In-house materials included: service-specific handouts, a document entitled *Teaching Prior to Weekend Pass* and a draft *Discharge Handbook*. An unstructured online search of SCI-related websites identified additional resources: *RehabTeamSite*,²¹ *Spinal Cord Injury Information Pages*,²² SCI rehabilitation checklists from various centers, the Consortium for Spinal Cord Medicine Consumer Guides,²³ and SCI Rehabilitation Evidence (SCIRE).²⁴ A Medline literature search (2000–2009) using the MeSH terms spinal cord injuries & patient education yielded five articles addressing the educational needs of patients with SCI.^{1–5} The results of the above environmental scan were then used to generate a preliminary list of handouts for stakeholder feedback.

Two 1.5 h focus groups were conducted and led by a facilitator and a member of the project team: (1) a consumer focus group consisting of persons with SCI, an attendant care coordinator and family members ($n = 7$); and (2) a

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multi-disciplinary staff focus group ($n=8$). The groups addressed (1) usefulness of written materials, (2) potential additions and (3) format and methods of delivery. Participants signed informed consent and were compensated. Audio recordings were reviewed by the project team who extracted salient points. One-on-one meetings were conducted with professional practice leaders from each of the inpatient services: physiotherapy, occupational therapy, psychology, social work, therapeutic recreation, chaplaincy, dietary, nursing, respiratory therapy and community and homecare services. Representatives provided feedback about (1) handout additions, (2) high-priority handouts and (3) commonly encountered languages other than English.

Development of educational materials

Staff members were recruited to write one or more high-priority handouts. Prospective writers were provided guidelines, a template and instructions for creating easy-to-read handouts—limit handout length (<4 pages), focus on practical information and minimize technical terms. As an incentive, staff members received gift certificates following the submission of initial drafts. Draft handouts were revised and returned to the original authors for final approval. An illustrator prepared required images, a photographer conducted photo shoots and a graphic designer participated in branding.

Implementation

Preparations included the development of promotional materials, a center-wide information session, meetings with inpatient services, training sessions and center-wide emails. On June 20, 2011 binders with a few key handouts were distributed to all inpatients. Designated filing cabinets containing the full series of handouts were placed in convenient locations throughout the hospital. Locations included the inpatient units, the outpatient department, the therapeutic gym, the center's resource center and staff offices. Colour-coded posters above the cabinets provided a quick reference for locating handouts divided into the following categories: Self-Management (Activities of Daily Living, Bladder, Bowel, Medical, Mobility, Skin, Emotional Health), Community Living (Equipment, Transportation, Financial Programs, Recreation, Home Environment and Care) and Organization (Figure 1).

On the launch day, a promotional event was held in the lobby to raise awareness. Staff training and orientation continued for approximately 2 months following initial launch. Activities included presentations at staff meetings, the creation of reference documents for those unable to attend and small group sessions to answer questions and highlight handouts relevant to specific disciplines. A binder with the full series of handouts was also provided to each service for reference and browsing. Handouts were also distributed on USB devices and made available online for public access in September 2012 at www.spinalcordessentials.ca.

Evaluation

Following the launch, surveys were distributed to patients and staff. The survey was adapted from a Website Evaluation Questionnaire²⁵ to address the usability of the physical binder and handouts: structure, layout, comprehensiveness, relevance, organization, comprehensibility and user-friendliness. Open-ended questions solicited general feedback from staff and patients, including pros and cons. Written surveys were completed by staff, whereas patients participated in telephone surveys following discharge. Responses to open-ended questions were summarized by extracting themes. Mann-Whitney U tests determined whether there were significant differences between patient and staff responses ($P \leq 0.05$). Participants provided written or verbal consent, and data collection was approved by the UHN-TRI's Research Ethics Board.

Utilization of available handouts was tracked for 2 years following implementation in order to determine the most frequently used handouts. Tracking was performed every 3–6 weeks by noting when refills were required for each cabinet. Individual folders were refilled with 20–25 handouts, when there were less than approximately eight handouts.

RESULTS

Summary of content and operations

A list of 109 potential handouts was compiled from the environmental scan. An additional 23 handouts were recommended by the focus groups covering topics such as orientation to the rehabilitation center and surrounding area, available services after discharge (for example, housing and attendant care) and follow-up schedules for medical appointments. Attendees suggested that a binder with accompanying handouts would be ideal; however, materials should be available electronically for individuals who have difficulty manipulating a binder (for example, persons with tetraplegia).

Following one-on-one meetings and additional discussion within the project team, the final list consisted of 156 handouts with 83 designated as high priority. For phase 1, 57 writers contributed to writing and finalizing 72 handouts (Figure 2). Seven were introductory materials or worksheets with limited content. The complete list of available handouts is provided in the Appendix. Remaining high-priority handouts, addressing predominantly sexuality and pain management, require additional editing and will be made available in the second phase of the project.

The binder is organized into eight colored tabs: Planning, Medical, Self-Care, Mobility, Community, Finances, Contacts and Other. Binders initially contain a small number of handouts relevant to all inpatients. During the course of inpatient rehabilitation, each patient's binder is customized by incorporating additional materials relevant to that specific patient. To help patients organize their binders, individual handouts incorporate a colour-coded icon that corresponds to the recommended tab for filing in the binder. The majority of handouts have been translated into French, Chinese and Farsi, and can be downloaded without cost at www.spinalcordessentials.ca. Additional languages are planned in the future.

Spinal Cord Essentials has also been integrated into staff orientation. New staff, students and volunteers have found the handouts to be informative for their own professional development as well as understanding specific rehabilitation teachings, which occur at the center. Relevant handouts are made available at biweekly patient and family education workshops. Volunteers assist in day-to-day activities including restocking cabinets, preparation/delivery of binders to units, printing handouts and orientation of patients to the binder.

Utilization

Three hundred and twenty-one folder refills were documented in the 2 years following launch. Inpatient units and the patient resource center showed the highest usage with an average of 3.33 folder refills per month. The gym and outpatient services were refilled approximately once per month, whereas physiotherapy and occupational therapy services required refills approximately every other month. Handouts that showed the highest usage addressed medical management, mobility and activities of daily living (Table 1).

Patient and staff feedback

Twenty staff and 27 patients completed questionnaires. Ratings were high for all questionnaire scales (Figure 3), and no significant differences were found between staff and patient responses. Staff members generally commented that Spinal Cord Essentials was convenient, aided with teaching patients, improved consistency and quality of staff training and assisted with teaching outside one's immediate area of expertise. Some indicated that additional handouts were needed to enable them to take full advantage of the project. A few staff members indicated that usage of the materials had not yet been incorporated into their routine and that their patients would not

Figure 1 Poster and cabinet containing hard copies of the handouts used in multiple areas around the rehabilitation centre.

make good use of the materials. Patients found the binder helpful for organizing the various materials received. A few patients indicated that the binder was not helpful because of a preference to retrieve information online. Also, some patients indicated that staff should be more proactive in providing them with handouts during their stay.

DISCUSSION

Effective education provides individuals with SCI and their families with the knowledge and skills required to self-manage their condition and maintain health. Shorter rehabilitation lengths of stay²⁶ reduce opportunities for teachable moments and increase the likelihood of patients being discharged before having acquired important knowledge and skills to prevent secondary health complications.^{5,6} It is therefore imperative that patient and family education be delivered efficiently and effectively. In recognition of the above, UHN-TRI augmented its efforts in this area by hiring a dedicated patient and family educator, opening a new SCI information center and expanding the patient and family education workshop series. Spinal Cord Essentials compliments each of these new efforts.

Ideally, patient education should be designed and delivered according to principles of adult learning theory, which help patients develop skills for self-directed lifelong learning.⁷ Redundancy and repetition spread across teaching strategies is optimal in order to accommodate different learning styles.^{5,6,27} Making materials available in multiple formats ensures that relevant information is accessible whether patients are at the rehabilitation center or in the community.

Spinal Cord Essentials is grounded in prior recommendations for optimizing patient education. Wolfe *et al.*⁸ recommended that an ideal educational resource would involve a customized patient binder, which would be populated as teachable moments arise. In addition, Spinal Cord Essentials adheres to the characteristics of effective patient education:²⁸

- Primacy. Handouts are limited to important, practical information.
- Brevity. The handouts are brief (1–4 pages).
- Organization. Handouts contain clear headers and are organized into thematic categories; which guide filing and are displayed on informational posters.
- Specificity. Instructions are clearly outlined, bulleted and numbered when possible.

Male Intermittent Catheterization

Intermittent catheterization (IC) is the insertion of a hollow tube called a catheter into the bladder to drain urine. This is done at regular intervals. The messages from your brain to empty your bladder may be disrupted after a spinal cord injury. If you are not able to urinate, your doctor may recommend intermittent catheterization to help you empty your bladder.

How can ICs help me?

- Keeps you dry and helps prevent skin breakdown caused by moisture
- Prevents infection from urine left in the bladder
- Preserves the ability of your bladder muscle to stretch
- Prevents bladder from getting too full and pushing urine back into your kidneys

Male Position

- Sitting in bed with your knees bent and pointing out
- Side lying in bed
- Sitting in your wheelchair
- Sitting on the toilet
- Standing in front of the toilet

Contact your Nurse for more information.

Created by: Sandi Disher	Updated: 2011-03-01
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SEL-BLA03

Figure 2 Example of handout layout.

Table 1 Handout usage across cabinet locations

Patient units	Resource center and outpatients	OT/PT/GYM
Diet and bowel management	IC protocol	Dressing techniques
Male IC	Cleaning your drainage bag	Autonomic dysreflexia
IC protocol	Autonomic dysreflexia	Standing step transfer
Stool softeners and laxatives	Pressure ulcer prevention	Car transfer with assistance
Community transportation	Outpatient services	Floor to chair transfers
Urinary tract infections	Diet and bowel management	Fall safety for wheelchair users
My bowel care program	Planning to go out	Pressure-relief techniques
Autonomic dysreflexia	Digital stimulation	Where to get cheap equipment
Pressure ulcer prevention	Pressure-relief techniques	Stairs for manual chair users
Digital stimulation	—	Pressure ulcer prevention
—	—	Lateral transfer

Abbreviation: IC, intermittent catheterization.
Handouts are listed in descending order of usage.

- Repetition. Materials are supplementary to workshops, point of care teaching and other available written materials.
- Literacy level. Handouts are written at an 8th grade reading level.

Spinal Cord Essentials is novel in that it differs from lengthier documents and books which are currently available.^{14–20} Lengthier documents are useful references but are not optimal for teaching specific skills in the moment. The format of Spinal Cord Essentials allows information to be delivered in a salient manner, while focusing on the practical. Matter *et al.*¹ found that compared with books and public libraries, handouts and brochures are preferred formats for information delivery; however, the most commonly preferred method for information delivery was the internet.

Figure 3 Average scores for patients and staff on the scales of the binder evaluation questionnaire. Error bars denote s.e.m.

Among community dwellers with SCI and other disabilities, there is an increased interest in internet-based health information resources.^{1,2,29–31} Although online learning can be helpful during inpatient rehabilitation, it is especially important following community integration. Patients may not be motivated or ready to learn about different aspects of their injury until a dire need arises.⁷ The availability of a personalized reference binder (compiled during inpatient rehabilitation) and online materials help ensure information is accessible when needed. The handouts are also being used to train private caregivers in the specific care needs for people with SCI living in the community.

Traditionally, a limitation of internet-based resources has been the accuracy and quality of information.^{2,32} Increasingly, SCI health information resources published by reputable sources are becoming available online.^{18–23,33,34} Spinal Cord Essentials is available online as PDF files at www.spinalcordessentials.ca in English, French, Chinese and Farsi. An additional resource that has been integrated into the SCI rehabilitation program at UHN-TRI is www.SCI-U.ca, which consists of a series of 10 e-learning courses.³³ The use of audio and visual media, expert opinions, peer interviews and endorsement by multiple SCI rehabilitation centers across Canada renders it a highly valued complementary educational resource for people with SCI.

The first phase of Spinal Cord Essentials addressed the most immediate aspects of inpatient rehabilitation including self-care, mobility, financial programs and home modifications. Handout usage has revealed great interest in medical management, mobility and activities of daily living. Prior studies have investigated the educational needs of persons with SCI, and personal care and potential health complications were often rated as most important.^{1–5} Additional areas of interest include aging, research, financial aid, support group information and community integration.^{3–5} Of the 156 candidate handouts that were identified, less than half have been brought to publication. Clear gaps in information still exist, notably in the areas of sexuality, medications and pain management. The next phase of Spinal Cord Essentials will prioritize these topics.

The initial emphasis was placed on assessing how the resource was received by staff and patients. Although the evaluation of the impact of Spinal Cord Essentials on the efficacy of patient and family education is being considered in the future, a significant barrier includes the relative lack of a validated outcome measure to assess patient learning about SCI. In addition, isolating the contribution of a single component of an institution-wide educational initiative may not be possible.

The high average scores on the usability questionnaire scales suggest that staff and patients were satisfied with most aspects of

the resource. Scoring lowest was the question on comprehensiveness, which underscores the importance of releasing additional handouts in the future. This was reinforced through the qualitative feedback where some staff indicated that additional handouts would be required for them to take full advantage of Spinal Cord Essentials. Also of interest, some patients indicated that the binder did not align with their learning styles and that digital sources were preferred.

The physical presence of Spinal Cord Essentials (for example, cabinets and posters) has helped increase the general awareness of patient education. Furthermore, handouts are now frequently being used for staff training and orientation. Handouts helped increase the homogeneity of procedures taught across the center and have provided staff with the confidence to provide information to patients that is outside their immediate area of expertise; two common barriers to patient education.^{7,28}

Written materials must be periodically revised and ongoing funding, infrastructure and staff are required. Spinal Cord Essentials has secured funding through sponsorship and vendor advertisements in the binders. At the time of this publication, no ads have been placed on the website; however, this is being considered. With the help of ongoing funding, the next phases of the project will be actualized including the release of new handouts, an update of the website and translation into additional languages.

CONCLUSION

Spinal Cord Essentials is a unique patient education resource comprised of a series of concise, practical handouts, which highlight specific ways in which individuals with SCI can self-manage their condition, troubleshoot financial and service needs and access community resources. It has been developed to complement existing strategies and resources and is freely available online at www.spinalcordessentials.ca.

DATA ARCHIVING

There were no data to deposit.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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APPENDIX**Self Management****Activities of Daily Living**

Dressing Techniques
Bathing
Eating and Drinking

Bladder

Condom Catheters
Foley Catheters
Male Intermittent Catheterization
Female Intermittent Catheterization
Intermittent Catheterization Protocol
Urinary Tract Infections
Cleaning Your Drainage Bag
Bladder Supply Vendors

Bowel

My Bowel Care Program
Digital Stimulation
Stool Softeners and Laxatives
Diet and Bowel Management

Emotional Health

Spiritual Care Resources
Social Work Services

Medical

Orthostatic Hypotension
Lung Volume Augmentation
Autonomic Disreflexia
100,000 km Tune Up
What is Spinal Cord Injury
My Diagnosis and Outcomes

Skin

Pressure Ulcer Prevention
Pressure Relief Techniques

Mobility

Lateral Transfer
Standing Step Transfer
Car Transfer with Assistance
Floor to Chair Transfer
Mechanical Lift Instructions
Bath Tub Transfer
Commode Transfer
Fall Safety for Wheelchair Users
Fall Safety for Ambulators
Stair Climbing for Ambulators
Stair Climbing for Manual Chair Users

Community Living**Equipment**

Where to Get Cheap Equipment
Assistive Devices Program
Choosing Your Equipment Vendor

Transportation

Getting Around as an Inpatient
WheelTrans Instructions
Returning to Driving

Recreation

Fitness Centres and Therapeutic Pools
City of Toronto Welcome Policy
Planning To Go Out

Home Environment and Care

Temporary Bathroom Accessibility
Temporary Ramps for Home Access
Supportive Housing Options
Transitional Living
Attendant Outreach Services
Direct Funding for Attendant Care
Supportive Service Living Units
Community Care Access Centre
MILE Life Skills Program

Financial Programs

Ontario Disability Support Program
Ontario Works
Canada Pension Plan Disability Benefits
Employment Insurance Sickness Benefits
Trillium Drug Program

Organization

Introduction to Spinal Cord Essentials
Acknowledgements
Weekly Personal Calendar
Appointments List
Questions for Health Care Professionals
My Goals for Rehab
Communication
Getting Ready for Discharge
Outpatient Services
My Spinal Cord Rehab Health Team
Contacts
Canadian Paraplegic Association Ontario
Lyndhurst Centre Fitness Centre