Priorities and Interventions in SCI Rehabilitation: Incorporating the Patient’s Voice Using PROMs

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Needs and priorities of patients change throughout the SCI continuum.
During the acute care phase . . . .

- Priority: loss of motor function (walking, hand/arm function, respiratory function)
- Patients have a limited ability to retain any information during acute care
- Perspectives of patients and families differ
- Development of clinical prediction rules can assist clinicians in counseling their patients regarding ‘priority areas’
During the community phase . . . .

- Priority: management of body functions (bowel, bladder, sexual function), arm/hand function (tetraplegia) and mobility (paraplegia)
- Adaptation – response shift
- Development of self-management programs to ensure people with SCI can manage their health and participate in the community
Value of PROMs in SCI Rehabilitation

Aggregate Level Data

- Population
- SCI Centers

Patient Level Data

- Clinicians
- Patients

- Compare to Other Health Conditions
- Ensure Optimal Care Across Centers
- Screen and Inform Treatment
- Personalize Treatment
Personalizing Treatment for Patients Using PROMs

Opportunities

• Provide scores back to patients in a meaningful format
• Assess and monitor health
• Inform shared decision making and self-management

Considerations

• Must ensure patients know how to act on the information
• Must ensure services are available if needs are identified
• Changes in health often require behavior change
• Need to evaluate
spinal cord injury + your body

- Affects every physiological system
- Chronic and complex condition

- psycho-social issues
- respiratory problems
- cardiovascular complications
- autonomic dysreflexia
- trunk mobility issues/paralysis
- pressure ulcers
- bladder/bowel dysfunctions
- upper limb mobility issues/paralysis
- sexual dysfunction & infertility
- lower limb mobility issues/paralysis
- osteoporosis
- neuropathic pain
Importance of Self-Management

Self-management refers to the individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one’s condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life. Thus, a dynamic and continuous process of self-regulation is established [4].

Health Action Process Approach (HAPA)

(Schwarzer et al., 2011)

Slide provided by Dr. Dalton Wolfe
“Theory-based self-management to improve bladder health in persons with SCI”

Dalton Wolfe, PhD
(Principal Investigator)
Demographics

SCI QoL
• Bladder Management Difficulties (Short Form)
• Bladder Complications

University of Washington Self Efficacy Scale

Bladder Behavior Assessment and HAPA Items

Classify Patients
• Pre-intender
• Intender
• Actor

Tailor Information
• Pre-intender – Information Resources
• Intender – Action Plan
• Actor – Maintenance Plan
About Me

Please select statements all that apply

- I am aware of the need to empty my bladder.
- I am usually continent.

Please select the method that best reflect the bladder management technique you currently use

- Indwelling Catheterization (Urethral or

In the past, have any of the following conditions affected your urinary system?

- Urinary Tract Infections
- Urinary Incontinence or Leakage
- Bladder Cancer
- Bladder Injury
- Bladder or Kidney Stones
- Kidney Disease
- Reconstructed Bladder
- Other

When was the last time you had the following screening or assessments done by a healthcare provider?

- Bladder Ultrasound:
  - Within the last 12 months
  - More than 12 months
  - Never
  - I don't know

- Urodynamics Study:
  - Within the last 12 months
  - More than 12 months
  - Never
  - I don't know

If you've had any other screenings recently, let us know:

- X-ray
  - Within the last 12 months
  - More than 12 months
  - Never
  - I don't know
# My Bladder Health Risk Assessment

The next set of questions will help you reflect on what you do to keep your bladder healthy.

I always drink 6-8 cups of fluids a day.

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree nor Disagree
- [ ] Disagree
- [ ] Strongly Disagree

I know how to recognize the signs and symptoms of bladder problems (e.g. urinary tract infections, bladder stones, “high pressure / overactive bladder”).

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree nor Disagree
- [ ] Disagree
- [ ] Strongly Disagree

I know when to seek appropriate medical attention pertaining to my bladder health.

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree nor Disagree
- [ ] Disagree
- [ ] Strongly Disagree

I visit my doctor for annual checkups that include a bladder ultrasound and/or other bladder assessments (e.g. urodynamics, scope).

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree nor Disagree
- [ ] Disagree
- [ ] Strongly Disagree

My caregiver always wash their hands before and after I/my caregiver empty the drainage bag or switch to/from the leg bag.

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree nor Disagree
- [ ] Disagree
- [ ] Strongly Disagree

My caregiver always make sure to keep the insertion area clean, i.e. wash with soap and water regularly.
My Bladder Health Risk Assessment

Below is a summary which reflects your previous answers.

- **Symptoms**
  - At risk
  - Not At Risk

- **Fluid Intake**
  - At risk
  - Not At Risk

- **Hygiene**
  - At risk
  - Not At Risk

- **Checkups**
  - At risk
  - Not At Risk

- **Medical Attention**
  - At risk
  - Not At Risk

- **Empty Frequency**
  - At risk
  - Not At Risk

- **Empty Routine**
  - At risk
  - Not At Risk

The great news is that you will learn how to make changes, set goals and get support to improve your bladder health.
Lessons Learned

- PROMs provide valuable information
- Implementation can be challenging:
  - Individuals must be ready to receive the information (In-patient setting may be too early)
  - Individuals in the community are busy
  - Consider value of a peer mentor in providing the education (health coach)
- Self-management resources must be centralized (one stop shop)
- Technology must be accessible
FUTURE DIRECTIONS
Canadian SCI Network
Clinicians, Patients and Families Select Relevant Domains Across SCI Continuum

E.g. SCI QOL, Neuro-QoL, PROMIS
  - Physical
  - Mental
  - Social

PROMs

Implement into Care Across the SCI Continuum
  - Inform shared decision-making and self-management (behavior change)

Infrastructure
  - Peer mentors/health coaches
  - Data capture (in-hospital and remote)
  - Reporting (patients, clinicians, administrators-program, national)
  - Evaluation
Informed Self-Management

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Self-management comprises the interventions, training, and skills provided to individuals with spinal cord injury (SCI) that support them in effectively managing all aspects of their lives (see Figure 1.0).
Future Directions

Need to:

• Continue to engage people with SCI
• Understand ‘response shift’ following injury
• Study implementation of PROMs (e.g. behavior change)
• Consider effects of patient factors on ‘norms’ (e.g. age, # comorbidities)
• Continually evaluate (e.g. program indicators)

Goal:

*Personalized care (consider person, impact of injury, treatment goals) at each stage of the SCI continuum to ensure people with SCI can actively participate in their community.*
Acknowledgements

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