Research article

Impact of impairment and secondary health conditions on health preference among Canadians with chronic spinal cord injury

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Context/objectives: To describe the relationships between secondary health conditions and health preference in a cohort of adults with chronic spinal cord injury (SCI).
Study design: Cross-sectional telephone survey.
Setting: Community.
Participants: Community-dwelling adult men and women ($N = 357$) with chronic traumatic and non-traumatic SCI (C1-L3 AIS A-D) who were at least 1 year post-injury/onset.
Interventions: Not applicable.
Outcome measures: Health Utilities Index-Mark III (HUI-Mark III) and SCI Secondary Conditions Scale-Modified (SCS-M).
Results: SCS-M responses for different secondary health conditions were used to create "low impact = absent/mild" and "high impact = moderate/significant" secondary health condition groups. Analysis of covariance was used to examine differences in HUI-Mark III scores for different secondary health conditions while controlling for impairment. The mean HUI-Mark III was 0.24 (0.27, range, −0.28 to 1.00). HUI-Mark III scores were lower ($P < 0.001$) in high impact groups for spasms, bladder and bowel dysfunction, urinary tract infections, autonomic dysreflexia, circulatory problems, respiratory problems, chronic pain, joint pain, psychological distress, and depression compared with the low impact groups. As well, HUI-Mark III scores were lower ($P < 0.05$) in high impact groups for pressure sores, unintentional injuries, contractures, heterotopic bone ossification, sexual dysfunction, postural hypotension, cardiac problems, and neurological deterioration than low-impact groups.
Conclusion: High-impact secondary health conditions are negatively associated with health preference in persons with SCI. Although further work is required, the HUI-Mark III data may be a useful tool for calculating quality-adjusted life years, and advocating for additional resources where secondary health conditions have substantial adverse impact on health.

Keywords: Health status, Outcomes assessment (health care), Quality of life, Spinal cord injuries, Tetraplegia, Paraplegia, Utility theory

Introduction

Secondary health conditions associated with spinal cord injury (SCI) can have a significant effect on an individual's ability to maintain health, independence, and well-being. A secondary health condition is defined as physical or psychological health conditions that are influenced directly or indirectly by the presence of a disability or underlying physical impairment.[1] Commonly occurring conditions after SCI include spasticity, pressure sores, bowel and bladder problems, urinary tract infections, neuropathic pain, shoulder and joint pain, fragility fractures, autonomic dysreflexia, psychological distress/depression, and respiratory complications.[2–4]

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Individuals with SCI and secondary health conditions utilize a large number of medical resources and treatments, which contributes to a large cost burden.[5,6] The estimated annual economic burden of SCI in Canada is estimated at 3.6 billion dollars per year, and these costs are partly attributable to re-admissions for SCI-related health conditions.[7] For instance, over a 6-year follow-up period post-injury, persons with SCI were re-hospitalized 2.6 times more often, were 2.7 times more likely to have a physician contact, and required 30 times more hours of home care services relative to matched controls.[8] The presence of SCI-related secondary health conditions have also been shown to negatively impact on quality of life (QoL) and one's ability to fully participate in the community.[9,10]

Given the high burden to both the individual and to society[11] from a relatively low incidence trauma population (25 to 93 per million population in North America),[12–16] it is important to demonstrate the need for an appropriate level of resources to support the health needs of disabled individuals aging with SCI. Government agencies advocate for the use of cost-utility analyses for decision-making around interventions.[17] This type of economic analysis requires disease-specific health preference estimates that reflect the quality of the health state and allow morbidity scores to be summarized in one measure, thus allowing for cross disease or health condition comparisons.

Health preference, or a health utility score, relates to a person's state of well-being,[18–20] and is a single metric anchored at 0 (death) and 1 (perfect health).[21] The value represents a preference for a health state. Utilities can be measured through expert opinion, patients and surrogates. Formal direct and indirect methods of measuring utilities are recommended.[22] Multi-attribute utility theory provides a mechanism for quantifying the subjective value of health states by providing a quantitative expression of an individual's values, with preference for a given health outcome expressed as a score on the weighted sum of the dimensions and their relative weights.[23] These health state morbidities are measured across a group of individuals and aggregated into a utility score,[24] which can then be used as quality weight for calculating the number of quality-adjusted life years (QALYs) gained in cost-utility analyses.[25]

One prominent instrument for generating health preference values is the Health Utilities Index (HUI).[26] The HUI-Mark III is an interval-scaled health status classification system that examines vision, hearing, speech, ambulation, dexterity, emotion, cognition, and pain.[27] Advantages of the HUI-Mark III system include efficiency, validity and reliability.[28] Limitations include the variable weighting system and linked definitions for each level of functioning.[25]

Health preference values associated with secondary health conditions would enable more efficient economic analyses of prevention and treatment procedures for individuals with SCI. At this time, there has been little published work done with regard to health preference after SCI,[29,30] and only one has examined sexual dysfunction post-SCI.[31] The purpose of this study was to provide a league table or reference list of health preference scores for a number of secondary health conditions based on data obtained from a representative cohort of community-dwelling individuals with chronic SCI. Results from this study will enable future economic evaluations through calculation of QALYs.

Methods

Participants

Participants ($N = 357$) were former patients of Toronto Rehab's Lyndhurst Centre, a tertiary SCI rehabilitation center in Ontario, Canada. A total of 905 potentially eligible participants were identified from the Jousse Long-term Follow-up database and hospital health records. The Long-term Follow-up database is a research platform designed to track the long-term health and QoL outcomes of an aging cohort of Ontarians with SCI. Participants provide written consent for study participation and verbal consent for ongoing monitoring of their health status (see Refs [10,32] for a description). Eligible participants were English-speaking adults over age 18 years with chronic SCI of traumatic or non-traumatic etiology of 1 or more years duration.

Of 905 possible participants, 196 declined, 310 were lost to follow-up (deceased, incorrect contact information), 4 were ineligible, and 15 failed to participate in the study after obtaining consent. Hence, a total of 395 participants provided consent for study participation and data were obtained from 380 participants. Twenty-two persons with non-SCI etiologies, and one person with traumatic SCI with missing impairment data were excluded. Hence, the final sample consisted of 357 adults with traumatic and non-traumatic SCI (Table 1).

This study was approved by the Research Ethics Board of the Toronto Rehabilitation Institute, and all the applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed.

Table 1 Demographic and impairment characteristics

Variable	*N*	%	Mean (SD)
Sex			
Men	218	78.1	
Women	61	21.9	
Etiology			
Traumatic	279	78.2	
Non-traumatic	78	21.8	
Impairment			
Incomplete tetraplegia (AIS B–D)	119	33.0	
Complete tetraplegia (AIS A)	68	19.0	
Incomplete paraplegia (AIS B–D)	95	27.0	
Complete paraplegia (AIS A)	75	21.0	
Mean age (range) years			54.0 (24-89)
Mean years post-injury/onset (range) years			19.3 (2–65)
Marital status			
Married/common-law	185	51.8	
Single/divorced/separated/widowed	172	48.2	
Education			
≤ Post-secondary	110	30.8	
> Post-secondary	247	69.2	
Vocational status			
Working (full-/part-time/student/etc.)	159	44.5	
Not working (unemployed/retired)	184	55.5	
Mean perceived health (SD)			6.6 (1.9)
Mean number of secondary health conditions (SD)			7.2 (3.6)
Mean SCI-SCS (SD)			12.1 (7.7)
Mean HUI-Mark III (SD)			0.27 (0.27)

N = 357. Values expressed as *n* (%), mean (range), or mean ± SD.

Outcome measures

A.T. Jousse Long-Term Follow-Up Questionnaire

The A.T. Jousse Long-term Follow-up Questionnaire is a non-standardized survey of socio-demographics, impairment and health status post-SCI. For this study, data regarding age, gender, marital status, employment, and level of education are reported. With regard to impairment, data regarding years post-injury, neurologic level of injury (NLI), and the American Spinal Injury Association Impairment Scale (AIS)[33] are reported. AIS impairment grade (A, B, C, D) was determined by participants' responses to a series of guided interview questions designed by a physiatrist, and confirmed in the majority (67%) of the sample by chart abstraction. Verification of the participants' impairment was done by a research staff member who was trained to use the International Standards for Neurological Classification of Spinal Cord Injury (American Spinal Injury Association, Atlanta, Georgia, USA; InSTeP e-Learning Program, available at http://www.asialearningcenter.com/catalog/course.asp?id=1&cid=1). A SCI physiatrist reviewed the charts to derive NLI and AIS where required. Analysis of the reliability of self-reported AIS versus AIS obtained via chart abstraction revealed this is a reliable and valid approach[34]. In this analysis, the overall percentage agreement of impairment type, cause (etiology), severity (NLI and AIS), and date of injury was 99.6, 98.4, 87.4 and 56.8%, respectively. As well, over 70% of self-report AIS levels agreed with the data obtained via chart abstraction

In addition, participants were asked to rate their global health on a 10-point numeric scale used to assess health status, with 1 representing poor health and 10 representing excellent health. Capturing perceived health status provides the opportunity to obtain participants' subjective views on their health status in relation to the scores of health-related measures of QoL.[35]

SCI Secondary Conditions Scale-Modified

The SCS[36] is a 16-item scale that provides standardized definitions of secondary health conditions common to SCI, which records the presence and perceived impact of the secondary health condition by the respondent (0 = not present/insignificant to 3 = chronic problem/significant). The internal consistency of the scale has been found to exceed 0.76 across three time points and the test–retest reliability ranged from 0.569 to 0.805.[36]

On the basis of previous findings of self-reported secondary health conditions in our cohort,[3] we supplemented the existing SCS-M scale with an additional six secondary health conditions and definitions that were reviewed and validated by SCI clinicians with relevant expertise (see Appendix 1). We also accounted for the possibility of other health conditions, and allowed participants to report two additional conditions if needed.

In the original scale, total scores range from 0 to 48 and are derived from the sum of the problem ratings such that higher scores indicate greater overall problems with secondary health conditions. With the addition of the eight to ten items (including the two additional ones if needed), total scores ranged from 0 to 72.

Health Utilities Index-Mark III

The HUI-Mark III[26] is a comprehensive system for describing the health status of individuals, and for assigning a preference score to them. The scale is founded on multi-attribute utility theory and its scores are based on preference measures from a random sample of the general population. The scores are, therefore, referred to as utility scores, and represent community preference.

The HUI-Mark III comprises eight attributes: vision, hearing, speech, ambulation, dexterity, emotion, cognition, and pain. On the basis of a series of questions about typical functional ability over the past 4 weeks, a respondent is assigned to one of the five or six levels for each attribute.[26] Utility-based preference scores assigned to each attribute level are then combined using the multiplicative utility function: $u = 1.371$ $(u1*u2*u3*u4*u5*u6*u7*u8) - 0.371$ to arrive at an overall index for each respondent. Perfect health is rated at 1.000 and death, 0.000; negative scores reflect health states worse than death. The global utility score provides a quantitative measure of the health-related QoL associated with an individual's health state.

Although no work-to-date has been conducted using this measure in the SCI population, the HUI-Mark III has been found to be an acceptable, reliable, valid and responsive to clinically meaningful change for a variety of health populations,[28] including osteoporosis,[37] arthritis,[38] and total hip arthoplasty.[39] On the basis of the evidence, and review of other existing utility measures, it was determined that the HUI-Mark III had acceptable face validity for use in persons with SCI. For instance, the mobility section of the EQ-5D[40] is limited to questions about a person's ability to walk, and does not include wheeling or use of other mobility aids. As well, it did not have items related to hand function. An additional asset of the HUI-Mark III is that it has been validated for telephone data collection.[41]

Procedure

Letters of introduction to the study purpose and methods were mailed to potential participants ($N = 905$), who were then contacted by trained interviewers to obtain informed consent for participation. Interviewers were blind to the study analysis and collected data via telephone interview. Each interview lasted approximately 45 minutes. For participants who returned a signed consent form (70%), hospital charts were accessed to confirm their impairment and duration of injury (date of injury, injury etiology, NLI, and AIS). Upon completion, participants received a thank you note and a $5.00 retail gift card.

Statistical analysis

Descriptive statistics were used to report the demographic and impairment characteristics of the cohort, the frequency and severity of secondary health conditions (see Table 2), and health preference scores. The responses from the SCS-M for different secondary health conditions were used to create "low impact = absent/mild" and "high impact = moderate/significant" groups (see Table 3). These groupings were based on preliminary analyses using the full range of SCS-M responses, which revealed no differences between absent and mild impact categories or between moderate and significant impact categories. A series of analysis of covariance models were used to examine differences in HUI-Mark III scores for different secondary health conditions (e.g. no/low-impact pressure ulcer versus moderate/high impact pressure ulcer) while controlling for impairment (AIS A versus AIS B-D; tetraplegia versus paraplegia). These variables were controlled for because of the differences noted between impairment groups on HUI-Mark III scores when the data were examined with an analysis of variance. It should be noted that no gender differences emerged on HUI-Mark III scores. As well, there were no associations between age or years post-injury with HUI-Mark III scores. Finally, Pearson correlation coefficients were calculated to examine relationships among health status and health preference. Data were analyzed using SPSS (v 17). (IBM SPSS Statistics c/o IBM Corp. Armonk, NY, USA).

Results

The mean HUI-Mark III score for the sample ($N = 357$) was 0.27 ± 0.27, with scores ranging from -0.28 to 1.00. Fifteen percent of the sample had a HUI-Mark III score of 0 or lower, indicating a health preference equivalent to, or "worse than", death, and only one person with a non-traumatic etiology had a score of 1, which equates with "perfect health".

With regard to specific impairment groups, there was a main effect for completeness of injury (AIS A versus

Table 2 Frequency of secondary health conditions and impact

	Frequency (%)		Impact (%)		
Secondary health condition		None	Mild	Moderate	Significant
Muscle spasms (spasticity)	77.9	4.7	45.7	30.6	19.1
Joint and muscle pain*	70.6	1.2	36.7	42.6	19.5
Chronic pain	59.7	0.9	18.3	40.8	39.9
Circulatory problems	50.1	5.6	53.1	28.5	12.8
Bladder dysfunction	42.9	11.1	35.9	24.2	28.8
Bowel dysfunction	42.3	7.2	40.1	23.7	28.9
Urinary tract infection	40.3	4.2	35.4	33.3	27.1
Sexual dysfunction	33.9	8.3	20.7	23.1	47.9
Contractures	33.6	5.0	40.8	30.0	19.1
Postural hypotension*	32.8	6.0	66.4	19.0	8.6
Autonomic dysreflexia	30.0	7.5	49.5	22.4	20.6
Psychological distress	29.4	1.0	47.6	34.3	17.1
Respiratory problems	24.6	3.4	59.1	25.0	12.5
Pressure sores*	23.0	4.9	30.9	34.6	29.6
High blood pressure	22.4	12.5	51.3	27.5	8.8
Injury caused by loss of sensation	20.4	6.8	53.4	21.9	17.8
Depression	19.6	1.4	55.7	27.1	15.7
Neurological deterioration	18.8	9.0	53.7	17.9	19.4
Diabetes mellitus	11.2	10.3	38.5	41.0	10.3
Cardiac problems	10.1	16.7	38.9	22.2	22.2
Heterotopic bone ossification	6.4	17.4	43.5	17.4	21.7
Fracture	2.2	12.5	37.5	0.0	50.0

$N = 357$.

*Missing impact score for one participant.

AIS B–D), F (1, 2.101) = 33.120, $P = 0.000$, and level (tetraplegia versus paraplegia), F (1, 1.277) = 20.124, $P = 0.000$, but the interaction of completeness and level were not significant. The mean HUI-Mark III scores for persons with complete and incomplete injuries were 0.18 ± 0.19 and 0.33 ± 0.30, respectively. For tetraplegia and paraplegia, the mean HUI-Mark III scores were 0.22 ± 0.27 and 0.32 ± 0.30, respectively.

Table 2 provides an overview of secondary health condition incidence and severity. The most common occurring secondary health conditions for the cohort were spasms (77.9%), joint and muscle pain (70.6%), and chronic pain (59.7%). In terms of secondary health condition severity, fractures were rated as being the most severe (57.1%). Other high impact conditions included sexual dysfunction (47.9%), chronic pain (3.9%), and pressure sores (29.6%).

Table 3 provides an overview of the HUI-Mark III scores by secondary health condition impact. Severity (AIS A versus BCD) and level of injury (tetraplegia vs paraplegia) were significant covariates for all of the listed secondary health conditions ($P = 0.0001$).

When examining relationships among health and health preference, self-rated health, total number of secondary health conditions and SCS-M severity were all associated ($P = 0.01$) with HUI-Mark III ($r = 0.37$, -0.41, and -0.47, respectively).

Discussion

Our findings suggest that higher health preference scores in community-dwelling persons with SCI were moderately associated with better self-perceptions of health; whereas lower scores were moderately associated with reporting a high number of secondary health conditions and higher health condition impact. As well, the majority of reported secondary health conditions significantly lowered health preference for individuals who did not report a particular condition (i.e. pain versus no pain, etc.). The lack of association observed for some health conditions (i.e. high blood pressure, fractures, etc.) may be attributable to their lack of impact on a specific domain of functioning, the silent nature of the underlying disease process or other confounders not included in our models. Overall, these findings provide evidence that the HUI-Mark III is a potentially sensitive tool for quantifying the impact of secondary health conditions on health-related QoL.

In terms of the impact of specific secondary health conditions, our findings are similar to those of Westgren and Levi,[42] who found that different secondary health conditions negatively impact health-related QoL in community-dwelling persons with SCI as measured by the Short-Form 36 (SF-36).[43] Although the metric of the SF-36 and HUI-Mark III are different, both measures are considered objective measures of

Table 3 Secondary health condition impact on HUI-Mark III scores

Secondary health condition	Impact group (n)	Mean HUI-Mark III (SD)
Pressure sore*	None/mild ($n = 305$)	0.29 (0.27)
	Moderate/significant ($n = 52$)	0.14 (0.22)
Injury caused by loss of sensation*	None/mild ($n = 328$)	0.28 (0.27)
	Moderate/significant ($n = 29$)	0.11 (0.22)
Muscle spasms (spasticity)†	None/mild ($n = 219$)	0.31 (0.28)
	Moderate/significant ($n = 138$)	0.20 (0.23)
Contracture*	None/mild ($n = 292$)	0.29 (0.27)
	Moderate/significant ($n = 65$)	0.18 (0.22)
Heterotopic bone ossification*	None/mild ($n = 348$)	0.27 (0.27)
	Moderate/significant ($n = 9$)	0.08 (0.15)
Diabetes mellitus	None/mild ($n = 337$)	0.26 (0.27)
	Moderate/significant ($n = 20$)	0.29 (0.31)
Bladder dysfunction†	None/mild ($n = 276$)	0.29 (0.28)
	Moderate/significant ($n = 81$)	0.19 (0.23)
Bowel dysfunction†	None/mild ($n = 277$)	0.29 (0.27)
	Moderate/significant ($n = 80$)	0.17 (0.24)
Urinary tract infection†	None/mild ($n = 270$)	0.30 (0.28)
	Moderate/significant ($n = 87$)	0.15 (0.18)
Sexual dysfunction*	None/mild ($n = 271$)	0.28 (0.26)
	Moderate/significant ($n = 86$)	0.21 (0.27)
Autonomic dysreflexia†	None/mild ($n = 311$)	0.29 (0.27)
	Moderate/significant ($n = 46$)	0.11 (0.19)
Postural hypotension‡	None/mild ($n = 325$)	0.28 (0.26)
	Moderate/significant ($n = 32$)	0.13 (0.22)
Circulatory problems†	None/mild ($n = 283$)	0.29 (0.27)
	Moderate/significant ($n = 74$)	0.16 (0.22)
Respiratory problems†	None/mild ($n = 324$)	0.28 (0.26)
	Moderate/significant ($n = 33$)	0.08 (0.25)
Chronic pain†	None/mild ($n = 185$)	0.34 (0.26)
	Moderate/significant ($n = 172$)	0.19 (0.25)
Joint and muscle pain†	None/mild ($n = 201$)	0.32 (0.28)
	Moderate/significant ($n = 156$)	0.19 (0.24)
Cardiac problems*	None/mild ($n = 341$)	0.27 (0.26)
	Moderate/significant ($n = 16$)	0.14 (0.31)
High blood pressure	None/mild ($n = 328$)	0.26 (0.27)
	Moderate/significant ($n = 29$)	0.29 (0.27)
Fracture	None/mild ($n = 350$)	0.27 (0.27)
	Moderate/significant ($n = 7$)	0.20 (0.26)
Neurological deterioration†	None/mild ($n = 332$)	0.28 (0.27)
	Moderate/significant ($n = 25$)	0.13 (0.25)
Psychological distress†	None/mild ($n = 303$)	0.29 (0.27)
	Moderate/significant ($n = 54$)	0.11 (0.23)
Depression†	None/mild ($n = 327$)	0.28 (0.27)
	Moderate/significant ($n = 30$)	0.07 (0.19)

*$P < 0.01$; †$P < 0.0001$; ‡$P < 0.05$.

health-related QoL, which evaluates statuses (in this instance, health) in terms of societal norms and standards.[44]

Having a SCI and related secondary health conditions negatively impacts health preference, and scores for the SCI population on the HUI-III ($M = 0.27$) appear to be comparable or lower than those scores found in the general and other health populations. The mean HUI-Mark III score for the general population has been reported as 0.93,[18] for stroke 0.58[45] to 0.68,[46] for arthritis/rheumatism 0.77[45] to 0.78,[46] for multiple sclerosis 0.57,[47] for Parkinson's disease 0.42,[48] and for Alzheimer's disease 0.45[45] to 0.58.[46]

It is noteworthy that when combing the literature for range of scores reported for the HUI-Mark III, none were identified by our group, whereas 15% of our sample reported a HUI-III score of 0 or less, indicating a health preference equivalent to, or "worse than", death. The HUI-Mark III allows for negative scores, with the lowest possible score being −0.36.[49] For the majority of secondary health conditions, the presence of a perceived moderate to significant impact condition negatively influences health preference. As such, the study findings suggest that SCI, even after controlling for impairment, is a high-impact disability, which is congruent with findings in the literature regarding

Table 4 HUI-Mark III scores for different health populations

Authors	Diseases	*N*	HUI-3 mean score (±SD)	Country
Asakawa *et al.*[38]	Arthritis	N/A	0.17 Household, proxy 0.08 Household, self-report 0.09 Institution	Canada
Mo *et al.*[51]		8460	0.40	Canada
Edwards *et al.*[52]	Stroke	173 674	0.60 ± 0.35 0.74 ± 0.21	Canada
Mo *et al.*[51]		1605	0.13	Canada
Haacke *et al.*[53]		152	0.47 ± 0.40	Germany
Asakawa *et al.*[38]	Alzheimer	N/A	0.42 Household, proxy 0.19 Household, self-report 0.08 Institution	Canada
Mo *et al.*[51]		162	0.07	Canada
Puhan *et al.*[54]	COPD	177	0.20 ± 0.15	Canada, USA
Mo *et al.*[51]		653	0.11	Canada
Sikdar *et al.* [55]	Diabetes	296	0.78 (0.75–0.81)	Canada
Mo *et al.*[51]		3102	0.20	Canada
Jones *et al.*[56]	Multiple Sclerosis	302	0.57 (0.52–0.63)	Canada
Mo *et al.*[51]		227	0.01	Canada
Pressler *et al.*[57]	Heart Failure	171	0.49 ± 0.34	USA
Mo *et al.*[51]		922	0.08	Canada

the significant societal costs associated with its management.[50] This is particularly evident when comparing the HUI-III results from our cohort to data obtained from other patient populations that are conventionally admitted for inpatient rehabilitation and recognized as vulnerable groups among members of the general population (see Table 4).

With regard to the SCI population, our data are somewhat comparable with previous reports. For instance, the health preference score for a sample of individuals receiving care from a U.S. Veterans Administration SCI program was significantly higher ($P < 0.05$) in persons with paraplegia ($M = 0.56$) compared with those with tetraplegia ($M = 0.53$).[29] As well, those who reported upper body functional impairments had lower scores than those with none (0.53 versus 0.58, $P < 0.01$).

Although the pattern of outcomes are similar to those, the health preference scores reported by Andresen *et al.* [29] are much higher ($M = 0.55$) than ours ($M = 0.24$). A likely reason for this discrepancy is attributable to using different outcome measures for generating health preference. In the study by Andresen *et al.*,[29] they assessed their sample by the quality of well-being (QWB) scale,[58] which uses four domains to develop an estimate that "people" would make of the relative desirability of life. The domains include mobility, physical activity, social activity, and takes into account symptoms and other medical problems (e.g. pain/weakness torso/arms/legs, general tiredness, major burn, upset, depressed and overweight). A similar range of scores to Andresen *et al.*[29] were obtained by Phillips *et al.*,[30] who examined the impact of a telehealth intervention on recently discharged patients with SCI. In addition to differences in domains, the scoring algorithms for the HUI-Mark III and QWB differ, which likely contribute to the differences of our scores and those of others.[22]

Study limitations

This study is subject to the limitations common to all cross-sectional surveys where bias regarding information is time, recall and health state dependent. In addition, our cohort of SCI participants is aging and may report health preference differently than a similar cohort with sub-acute SCI. Ideally, the presence or absence of the SHC and its severity could be validated by a regulated health care professionals. Perhaps most importantly, the psychometric properties of the HUI-Mark III for the SCI population have not previously been established. A host of psychometric issues regarding HUI-Mark III data reliability, acceptability and feasibility, floor and ceiling effects, etc. needs to be addressed in future large-scale prospective studies. In addition, our modifications to the SCS require review of its psychometric properties. Given these issues, we express some caution regarding the generalizability of our findings as a definite reference guide for health preference states associated with secondary health conditions after SCI. Despite these limitations, our preliminary analyses on the HUI-Mark III showed promising convergent validity with the Spinal Cord Independence Measure-III,[59] and divergent validity with subjective measures of QoL and community participation.[60] This work is on-going towards establishing the reliability and validity of the scale for use in SCI. As well, the HUI-Mark III has been widely used across many different health populations and has established norms for the able-bodied population,[49] which are useful for comparing burden of SCI to other health groups. As such, the use of the HUI-Mark III in SCI appears to be suitable given our findings that the scale is sensitive to SCI impairment and secondary health condition impact.

A larger conceptual issue with our study is the use of utility measures for quantifying health-related QoL. Some issues raised with measuring QoL as utility include a lack of sensitivity of existing tools (in particular to emotional states), the underlying clinometric approach to its development, which utilizes a single item or indicator to determine a person's status on a domain, and conceptual issues of defining "perfect health".[44] Regardless, there is a paucity of the literature regarding health preference in the field of SCI, and as such there is a need for further work on this topic as these type of data can complement subjective perceptions of QoL, and may be used to influence health policy and advocate for alternate/additional resources for the management of secondary health conditions after SCI.

Conclusions

In summary, this study provides a list of health preference scores for individuals with SCI according to impairment and secondary health condition status. The health preference scores provided have the potential to impact health policy, inform resource allocation, and enable health-related QoL studies, and future cost-utility analyses. These data are likely to facilitate future development of economic models by providing economists, researchers and policy-makers alike with health preferences reference values for secondary health conditions among Canadians living with chronic SCI.

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Appendix 1: Spinal cord injury secondary conditions scale modified additional items

☐ Cardiac problems	☐ 0 ☐ 1 ☐ 2 ☐ 3	An irregular heart rate often called atrial fibrillation or ventricular fibrillation. A heart attack occurs when blood supply to the heart muscle is blocked, and the muscle, or a part of it, dies. Heart failure occurs when the heart is not pumping effectively and fluid accumulates in the lungs
☐ High blood pressure	☐ 0 ☐ 1 ☐ 2 ☐ 3	High blood pressure is diagnosed by a doctor, and occurs when your systolic blood pressure is over 140 mmHg (top number) or your diastolic is over 90 mmHg (bottom number)
☐ Fracture	☐ 0 ☐ 1 ☐ 2 ☐ 3	A crack or break in a bone
☐ Neurological deterioration	☐ 0 ☐ 1 ☐ 2 ☐ 3	A reduction in your motor function and/or a negative change in your sensory function after discharge from rehabilitation
☐ Psychological distress	☐ 0 ☐ 1 ☐ 2 ☐ 3	This may be feelings of unable to cope effectively, a change in emotional status (e.g., anxious, depressed mood), mental discomfort, decreased self-esteem *Note*: There is a separate item for depression
☐ Depression	☐ 0 ☐ 1 ☐ 2 ☐ 3	Symptoms include depressed mood, loss of interest or pleasure, feelings of guilt or low self-worth. Depression is diagnosed and being treated by a physician or by a psychologist
☐ Other: ________________	☐ 0 ☐ 1 ☐ 2 ☐ 3	Additional information: ____ ____ ________________

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