Predicting health preference in chronic spinal cord injury

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Context/Objective: Health preference values relate to a person's state of well-being, and is a single metric anchored at 0 (death) and 1 (perfect health). Health preference plays a key role in health economics and health policy, particularly in interpreting the results of cost-effectiveness studies, and supports the allocation of healthcare resources. The current study used elements of the International Classification of Functioning, Disability and Health (ICF) framework to predict health preference in persons with spinal cord injury (SCI).

Methods: Data were collected by telephone survey on (1) demographics, (2) impairment (etiology, neurological level of injury, and ASIA impairment scale), (3) secondary health conditions (SHCs) using the SCI-Secondary Conditions Scale-Modified, (4) functional abilities using the Spinal Cord Independence Measure (SCIM), and (5) health preference using the Health Utilities Index-Mark III (HUI-Mark III) among adults with chronic SCI. Variables were categorized according to ICF headings and hierarchical regression analyses were used to predict HUI-Mark III scores.

Results: Adults with chronic traumatic or non-traumatic SCI ($N = 357$) reported a mean health preference score of 0.27 (± 0.27). In predicting health preference, our model accounted for 55.1% of the variance with "body functions and structure", and "activity and participation", significantly contributing to the model ($P < 0.0001$). In particular, older age, being employed, and having higher SCIM scores were positively associated with health preference. Conversely, a higher SHC impact score was associated with poorer health preference.

Conclusions: Variables representative of "activity and participation" largely influence health preference among persons with chronic SCI, which may be amenable to intervention. These findings could be applied to advocate for health promotion and employment support programs to maximize well-being in persons aging with chronic SCI in the community.

Keywords: Spinal cord injuries, Health preference, Health-related quality of life, ICF, Spinal cord independence measure, Secondary health conditions

Introduction

Despite having a relatively low incidence, spinal cord injury (SCI) is a high cost and high burden disability to both the individual and to society.¹ The total acute care costs of the index event (SCI onset), in-patient acute and rehabilitation stay and readmission in the first year following the index event in Ontario are substantial, at 123 674.00 (2005 \$CDN).² The direct medical costs of SCI remain high over the course of

an individual's lifetime. Recent data estimating the direct medical costs associated with traumatic SCI reported that the lifetime economic burden per individual ranges from \$1.5 million for persons with incomplete paraplegia to \$3.0 million for persons with complete tetraplegia.³

The majority of lifetime costs of care beyond the first year are derived from the multimorbidity of aging with an SCI, and the associated compromises of their health and functional abilities, as well as the increases in caregiver burden. Multimorbidity is defined as any combination of chronic disease with at least one other

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disease (acute or chronic) or biopsychosocial factor, including the social network, the burden of disease(s), healthcare consumption, and the individual's coping style.⁴ Moreover, multiple secondary health conditions (SHCs) following SCI, such as pressure ulcers, pain, spasticity, etc. negatively impacts healthcare costs,^{2,3} a person's well-being, and interferes with their ability to fully participate in the community.⁵

In order to demonstrate the need for an appropriate level of resources or interventions to support the health needs of individuals aging with SCI, government agencies advocate for the use of economic analyses for decision-making.⁶ Cost-utility analyses require health preference estimates that reflect the quality of the health state and allow these measures of morbidity linked with mortality to be summarized in one measure, namely the quality-adjusted life year (QALY).⁷ Health preference refers to:

*judgments of the desirability of a particular set of outcomes or situation that describes what is labeled 'good' or 'bad'. The term connotes the exact meaning of, value, desirability or utility of a health state.*⁸

Health preference (or health utility) values relate to a person's state of well-being, and is a single metric anchored at 0 (death) and 1 (perfect health), to numerically represent an individual or populations preference for a particular health state.⁹ Multiattribute 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.¹⁰ When a health preference value is multiplied with a given state of health by the years lived in that state, it generates a QALY.

The underlying idea of the QALY is the assumption that a year of life lived in perfect health is worth 1 QALY (1 year of life $\times$ 1 health preference value = 1 QALY) and that a year of life lived in a state of less than perfect health is worth <1 .¹¹ In order to determine the exact QALY value, it is sufficient to multiply the utility value associated with a given state of health by the years lived in that state. QALYs are therefore expressed in terms of "years lived in perfect health": half a year lived in perfect health is equivalent to 0.5 QALYs (0.5 years $\times$ 1 health preference), the same as 1 year of life lived in a situation with utility 0.5 (e.g. bed-ridden) (1 year $\times$ 0.5 preference).¹¹ When QALYs are incorporated with medical costs, it provides a final common denominator of cost/QALY. This parameter

can be used to develop a cost-effectiveness analysis of any treatment. This is then used to allocate healthcare resources, with an intervention with a lower cost to QALY saved (incremental cost-effectiveness) ratio ("ICER") being preferred over an intervention with a higher ratio.¹² Overall, the use of QALYs is a popular metric for policymakers since they allow for cross disease or health condition comparisons as they are often derived from generic outcome measures (i.e. SF-36) that have applicability to a wide variety of disease and/or disability groups.¹³ Given the importance and applicability of health preference values to decision-makers for generating QALYs, it is important that the analyses examining the effectiveness of interventions record health preference values. However, there is a paucity of evidence related to health preference or QALYs after SCI, and further work is needed.^{13,14}

In the absence of data, work to relate appropriate measures of health outcomes in the SCI population may be mapped onto health preference values. One suitable outcome measure is the International Classification of Functioning, Disability and Health (ICF), which is the endorsed framework of the World Health Organization for measuring health and disability at both the individual and population levels.¹⁵ Rather than emphasizing the cause of disability, the model shifts the emphasis on understanding the impact of disability, which thereby places all health conditions on an equal footing in order to allow for them to be compared using a common metric. Furthermore, ICF takes into account the social aspects of disability by including contextual factors, such as the impact of the environment on the person's functioning. The distinction between physical, psychological, and environmental factors provided by the ICF are useful for examining the impact of SCI since it can be used to capture the multitude of challenges this population typically contends with (e.g. SHCs, environmental barriers, etc.), and utilizes terms that are common to investigators and policymakers in the fields of rehabilitation, public health, and gerontology.¹⁶ Thus, employing the ICF's biopsychosocial model of disability can serve to provide the common language needed for evidence-based policy development.¹⁷

The main objective of this study is to use elements of the ICF framework in order to predict health preference in a community-dwelling group of persons aging with chronic SCI. Although our study was exploratory in nature, it was hypothesized that variables associated with poorer physical and mental functioning (i.e. functional ability, poor health) would predict lower health preference scores. For instance, data from the

Canadian population have shown that health preference scores decrease with age and with severity of disease or disability.¹⁸ Both health preference and the ICF framework provide common metrics across disability groups, and may frame our findings in terms that will support the advocacy for additional resources needed to help people with SCI maintain good health and well-being.

Participants

Participants were former patients of Toronto Rehab's Lyndhurst Centre, a tertiary SCI rehabilitation center in Ontario, Canada. Participants were identified from the Jousse Long-term Follow-up database,¹⁹ which tracks the long-term outcomes of persons aging with SCI in Ontario, and from hospital health records. Eligible participants were English-speaking adults over the age 18 years with SCI of traumatic or non-traumatic etiology of one or more years duration.

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

Outcome measures

A number of questionnaires were used to determine the relationship of SCI outcome measures and health preference values.

The A.T. Jousse Long-Term Follow-up Questionnaire

The A.T. Jousse Long-Term Follow-up Questionnaire collects data on sociodemographics, impairment, and health status post-SCI.^{5,19} With regard to impairment, data regarding etiology, years post-injury, neurological level of injury (NLI), and completeness of injury based on the American Spinal Injury Association Impairment Scale (AIS)²⁰ are reported. AIS impairment grade (A, B, C, and D) were 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 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, GA, 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 vs. AIS obtained via chart abstraction revealed self-report is reliable and valid, whereby

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. Furthermore, over 70% of self-report AIS levels agreed with the data obtained via chart abstraction.

SCI Secondary Conditions Scale-Modified (SCS-M)

The SCI-SCS²¹ is a 16-item scale that provides standardized definitions of SHCs common to SCI (i.e. muscle spasms, pressure sores, bladder dysfunction, bowel dysfunction, etc.), which records the presence and perceived impact of the SHC 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 timepoints and the test-retest reliability ranged from 0.569 to 0.805.²¹

We supplemented the 16-item SCI-SCS with an additional six SHCs and associated definitions (cardiac problems, high blood pressure, fracture, neurological deterioration, psychological distress, and depression) that were reviewed by SCI clinicians with relevant expertise, along with the option of reporting two other health conditions not covered on the list.¹⁶ In the original scale, the 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 SHCs. Within the current iteration, total scores could range from 0 to 72. Overall, higher scores on the SCS-M indicate greater SHC impact on the individual.

Spinal Cord Independence Measure (SCIM-III)

The Spinal Cord Independence Measure (SCIM-III) is a comprehensive ability rating scale that has been designed specifically for patients with spinal cord lesions.²² The SCIM score ranges from 0 to 100, and includes three areas of functional assessment (i.e. self-care, respiratory and sphincter management, and mobility) that are weighted according to their clinical relevance. The SCIM-III has been shown to be reliable and valid for functional assessment of individuals with traumatic and non-traumatic SCI.^{22,23}

Health Utilities Index-Mark III (HUI-Mark III)²⁴ is a comprehensive system for describing the health status of individuals, and for assigning a preference score to them. The scale is founded on multiattribute 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 health preference scores and represent community preference.

The HUI-Mark III comprises eight attributes: vision, hearing, speech, ambulation, dexterity, emotion,

cognition, and pain. Based on a series of questions about typical functional ability, a respondent is assigned to one of the five or six levels for each attribute.²⁴ Utility-based preference scores assigned to each attribute level are then combined using the multiplicative utility function: $u = 1.371 (u_1^* u_2^* u_3^* u_4^* u_5^* u_6^* u_7^* u_8) - 0.371$ to arrive at an overall index for each respondent. Perfect health is rated at 1.0 and death, 0.0; negative scores reflect health states worse than death. The global utility score provides a quantitative measure of the health-related quality of life (QoL) associated with an individual's health state.⁹

Methods

Letters of introduction to the study purpose and methods were mailed to potential participants, 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 ~45 minutes. For those 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 summarize the characteristics of the sample. Pearson correlation coefficients were used to examine associations among the variables (Table 2). The following demographic variables were dummy-coded to dichotomous variables (1 vs. 0) into the following groups: (1) sex (male vs. female); (2) AIS (CD vs. AB); (3) level (paraplegia vs. tetraplegia); (4) etiology (traumatic vs. non-traumatic); (5) marital status (married vs. single; "married" included persons who were common law; "single" also included people who were divorced or widowed); (6) education (higher than post-secondary vs. post-secondary or less); (7) employment (employed vs. unemployed; "employed" included students, homemakers, and volunteers); and (8) living situation (living with someone vs. living alone).

Hierarchical multiple regression analyses were used to predict health preference (HUI-Mark III). Variables assumed to be representative of "personal factors" were entered into the first block (age, sex, and education), followed by those representing "body functions and structure" (etiology, AIS, level group, and duration of injury), "activity and participation" (SCS-M, SCIM, and employment), and lastly followed by

"environmental factors" (living situation). Although some of the variables may arguably construe more than one domain of the ICF, our categorization of constructs is consistent with those proposed by others purporting the usefulness of the ICF for evaluating outcomes post-SCI.²⁵ It should be noted that data were examined to ensure that they did not violate the assumptions for regression (normality, multicollinearity, and heteroskedasticity), and all statistical analyses were performed using SPSS (version 17, SPSS Inc., Chicago, IL, USA).

Results

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 missing impairment data, were excluded. Hence, the final sample consisted of 357 adults with traumatic and non-traumatic SCI (Table 1).

Table 1 Demographic and impairment characteristics

Variable	Value	Percent
	(N = 357)	(%)
Sex		
Men	257	72.0
Women	100	28.0
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	53.7 (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
Employment status		
Working (full-/part-time/student/etc.)	134	37.5
Not working (unemployed/retired)	223	62.5
Living situation		
Living without support	101	28.3
Living with support	256	71.7
Mean # of SHCs (SD)	7.2 (3.6)	
Mean SCS-M (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.

Table 2 Pearson correlation coefficients among variables

	2	3	4	5	6	7	8	9	10	11	12
1. HUI Mark-III	0.079	0.036	-0.015	-0.154 [†]	0.272 [§]	0.191 [§]	-0.147 [†]	-0.465 [§]	0.646 [§]	0.236 [§]	0.078
2. Age	—	-0.08*	-0.102*	-0.289 [§]	0.221 [§]	0.059	0.189 [§]	0.063	0.027	-0.233 [§]	0.077
3. Sex	—	—	-0.042	0.270 [§]	-0.158 [†]	-0.148 [†]	0.099*	-0.160 [†]	-0.031	0.076	-0.036
4. Education	—	—	—	0.044	-0.087	0.005	0.001	0.046	-0.047	0.129 [†]	0.039
5. Etiology	—	—	—	—	-0.335 [§]	-0.188 [§]	0.202 [§]	-0.073	-0.146 [†]	0.074	-0.031
6. AIS	—	—	—	—	—	-0.079	-0.224 [§]	-0.011	0.389 [§]	-0.051	0.020
7. NLI	—	—	—	—	—	—	-0.027	0.058	0.289 [§]	0.014	0.001
8. YPI	—	—	—	—	—	—	—	0.005	-0.225 [§]	0.029	-0.012
9. SCS-M	—	—	—	—	—	—	—	—	-0.198 [§]	-0.249 [§]	-0.036
10. SCIM	—	—	—	—	—	—	—	—	—	0.109*	0.064
11. Employment	—	—	—	—	—	—	—	—	—	—	0.102*
12. Living situation	—	—	—	—	—	—	—	—	—	—	—

*P < 0.05.

†P < 0.01.

‡P < 0.001.

§P < 0.0001.

NLI, Neurological Level of Injury; AIS, American Spinal Injury Association Impairment Scale; YPI, years post-injury; SCS-M, Secondary Condition Scale-Modified; SCIM, Spinal Cord Independence Measure.

The mean health preference score of the sample was 0.27 (+0.27). In general, higher scores on the HUI Mark-III were associated with non-traumatic etiology, less SCI impairment (incomplete and paraplegia, SCIM), and being employed, while lower scores were associated with longer duration of SCI and higher scores on the SCS-M (Table 2).

With regard to the regression models predicting health preference, the addition of each set of variables produced a significant increase in the amount of

variance explained except for the first model consisting of “personal factors” and the fourth model, which included “environmental factors” (Table 3). The regression model explained 55.1% of the variance and was statistically significant ($P < 0.000$). An examination of the weights assigned to the predictor variables in the final analysis revealed that only four of the predictor variables made unique, statistically significant contributions to the predictive accuracy (Table 4). Being an older age, employed, and having higher SCIM scores

Table 3 Hierarchical regression model predicting HUI-Mark III scores

Block	R ²	Adjusted R ²	R ² change	Sig.
Model 1 – Personal factors	0.008	0.000	0.008	0.410
Model 2 – Body functions and structure	0.142	0.125	0.134	0.000
Model 3 – Activity and participation	0.565	0.552	0.422	0.000
Model 4 – Environmental factors	0.565	0.551	0.000	0.776

Table 4 Predictor weights of regression model predicting HUI-Mark III scores

Variable	B	SE of B	β	t	P of t
(Constant)	-0.110	0.071		-1.550	0.122
Age	0.002	0.001	0.094	2.319	0.021
Sex	0.019	0.022	0.032	0.853	0.394
Education	0.015	0.021	0.026	0.715	0.475
Etiology	-0.044	0.027	-0.068	-1.648	0.100
AIS	0.017	0.024	0.031	0.714	0.475
Injury level	0.025	0.021	0.046	1.164	0.245
Years post-injury	-0.001	0.001	-0.030	-0.761	0.447
SCS-M	-0.012	0.001	-0.342	-8.983	0.000
SCIM	0.006	0.000	0.522	12.041	0.000
Employment	0.064	0.021	0.116	3.007	0.003
Living situation	0.006	0.021	0.010	0.285	0.776

AIS, American Spinal Injury Association Impairment Scale; SCS-M, Secondary Condition Scale-Modified; SCIM, Spinal Cord Independence Measure.

were positively associated with health preference. Conversely, reporting a higher SHC impact score was associated with poorer health preference.

Discussion

The purpose of the study was to use the ICF model as a theoretical framework for predicting health preference in adults with chronic SCI living in the community. Our regression model accounted for a large amount of the variance (55.1%), and found that each model except for the initial block of “personal factors” and the last block of “environmental factors” were significant. In terms of specific variables, those associated with “activity and participation” were those driving the effect (SHC impact, SCIM scores, and employment), with one variable from the “personal factors” (age) becoming significant after the third model was entered.

Having a SCI and related SHCs 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.^{26–30} For instance, the mean HUI Mark III score for the general population has been reported as 0.93,²⁶ for stroke 0.58²⁷–0.68,²⁸ for arthritis/rheumatism 0.77²⁷–0.78,²⁸ for multiple sclerosis 0.57,²⁹ for Parkinson’s disease 0.42,³⁰ and for Alzheimer’s disease 0.45²⁷–0.58.²⁸ A full review on the impact of SHC severity post-SCI is reported by Craven *et al.*³¹

Overall, our hypotheses were confirmed with regard to the “activity/activity restrictions” in that we anticipated variables associated with poorer physical and mental functioning would predict lower scores on health. The relationship between lower health and SCIM was robust, and is consistent with previous findings of physical functioning being associated with health-related QoL.^{32,33} Similarly, poorer health and employment status have been found to also be associated with lower health-related QoL.³⁴ Our findings reinforce the notion that measures of physical function play an important role in directing the allocation of resources for management of SCI³⁵ but also highlight the need for taking into account the overall health status since SHCs (e.g. pressure ulcers) can put tremendous strain, in terms of costs to the healthcare system,³⁶ and may affect an individual’s ability to return to the workforce.

The finding that older age was associated with higher health preference was somewhat surprising given that older adults (able-bodied and disabled) tend to have lower scores than younger adults.¹⁸ Although health

status typically declines with age, so do the number of people in a cohort.³⁷ The current study is a cross-sectional analysis from an on-going cohort study of persons aging with SCI in Canada.³⁸ Overall, 87% of our samples were persons who were previously contacted for participation. As a result, older adults in the present study may not represent the “greatest societal burden of disability” since we may have sampled a relatively “healthy” group of older adults with SCI. Furthermore, socioeconomic status (SES) is correlated with health status, and age group may mitigate the size effect, with differences being relatively small at younger ages (i.e. entry level positions) and at older ages (i.e. retirement), while being greater among middle-aged groups.³⁹ Hence, health preference may have been more negatively experienced by our sample who were younger and unemployed, which may also account for why poorer scores on the HUI-Mark III were associated with younger age. Further work is needed to explore these relationships and to clarify issues among age, SES, and health-related QoL post-SCI.

This study is subject to the limitations common to all cross-sectional surveys where information is time-, recall-, and health state knowledge dependent. This may have influenced our findings, and in particular our results with regard to chronological age (i.e. survival effects). As well, the HUI-Mark III has not been validated for community-dwelling adults with chronic SCI. Although the HUI-Mark III has been widely used across many different health populations and has established norms for the able-bodied population,¹⁰ which are useful for comparing burden of SCI to other health groups, there are some underlying theoretical concepts which are problematic. Health preference scores are representative of “objective” measure of health-related QoL, which compares observable life conditions or physical functioning in relation to societal norms and standards.⁴⁰ Thus, the notion of “perfect health” or “worse than death” may be offensive to people with SCI, and they may object to this “societal” perspective reflected in the scoring of health preference as it may not correspond to their own insider or “subjective” views of their QoL.⁴⁰

Despite these limitations, framing our analysis within the ICF bolsters our ability to compare findings to other health populations as both approaches provide a common metric for policymakers and economists to facilitate comparisons across disability groups. Having a common framework and metric allows for improved communication of results, and will maximize future efficiency by limiting unintentional replication of studies,

allows for more effective meta-analyses,¹⁶ and will provide comparative economic evaluations with health preference values. As a result, our findings could be applied to lobby for funding for health promotion and employment support programs to maximize the well-being of persons aging with SCI, which in turn might ultimately minimize direct medical costs to the health-care system downstream.

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Conflicts of interest None.

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

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