Health behavior in persons with spinal cord injury: development and initial validation of an outcome measure

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Objective: To describe the development and initial psychometric properties of a new outcome measure for health behaviors that delay or prevent secondary impairments associated with spinal cord injury (SCI).

Design: Persons with SCI were surveyed during routine annual physical evaluations. **Setting:** Veterans Affairs Medical Center Spinal Cord Injury Unit, which specializes in primary care for persons with SCI.

Participants: Forty-nine persons with SCI, aged 19-73 years, 1-50 years post-SCI.

Main Outcome Measure: The newly developed Spinal Cord Injury Lifestyle Scale (SCILS). **Results:** Internal consistency is high ($\alpha = 0.81$). Correlations between clinicians' ratings of participants' health behavior and the new SCILS provide preliminary support for construct validity.

Conclusion: The SCILS is a brief, self-report measure of health-related behavior in persons with SCI. It is a promising new outcome measure to evaluate the effectiveness of clinical and educational efforts for health maintenance and prevention of secondary impairments associated with SCI.

Keywords: health promotion; behavior; rehabilitation; health behavior

Introduction

Costs and clinical effectiveness are the current focus of health care policy makers and insurers.¹ As a result, care providers are held increasingly accountable for demonstrating the efficacy of clinical interventions that are presumed to positively impact patients' health status. Although demands for accountability and clinical effectiveness may be perceived as burdensome by care providers, health benefits must be proven to justify expenditures in today's competitive marketplace. One strategy for the assessment of health benefits is the use of empirically validated outcome instruments to measure the effectiveness of clinical interventions. Empirically validated instruments may be especially relevant in the area of spinal cord injury (SCI) health care.

Following SCI, patients must learn a variety of new behaviors to manage their physical impairment and prevent further health complications.^{2,3} Some of these behaviors are critical for survival (eg, bowel and bladder management), while others maintain health and quality of life over the long-term (eg, smoking cessation and physical activity). As a result, education on health maintenance and prevention is a major goal of contemporary SCI rehabilitation.^{4,5} Yet, despite the

health education emphasis during acute rehabilitation, secondary impairments are prevalent in the SCI population^{3,6-9} and include chronic pain (90% of the SCI population),¹⁰⁻¹² pressure ulcers (50%),¹³ osteo-porosis,¹⁴ and pathological fractures (6%).¹⁴

Secondary impairments likely diminish overall health status and quality of life in persons with SCI and also may underlie the disproportionately high health care costs in this population. Health care expenditures for the SCI population are conservatively estimated at \$14 000 per person per year, for a total of more than \$3 billion above total annual health care costs for the noninjured population.¹⁵ Physician visits for persons with SCI are four times the rate of non-disabled adults¹⁶ and inpatient hospitalization expenses for the total SCI population were estimated at \$1.6 billion in 1991.^{17,18} Pressure ulcers alone have been reported to cost an average of \$58 000 per occurrence.¹⁹ Fortunately, most secondary impairments in persons with SCI can be significantly delayed or prevented by changes in health behavior.²⁰⁻²⁷ Delay or prevention of secondary impairments not only results in maintained quality of life, but also may significantly reduce overall health care costs for the SCI population.

In summary, the personal and financial consequences of secondary impairments are considerable,

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yet specific behaviors can significantly minimize their impact on persons with SCI. Interventions designed to increase health behaviors have the potential to reduce health care costs and enhance quality of life in this population. Before such interventions can be designed, improved, or evaluated, an instrument for measuring health behavior in persons with SCI is required. The purpose of this paper is to report the development and initial validation of a new outcome measure for health behaviors that delay or prevent the development of secondary impairments associated with SCI. The ultimate goal is to provide future investigators and health policy makers with a psychometrically sound instrument to assess the effectiveness of clinical interventions (eg, educational rehabilitation efforts) designed to maintain or improve health status and prevent SCI-related secondary impairments.

Method

Participants

Participants were 49 males who received primary care at a specialized Veterans Affairs Medical Center Spinal Cord Injury Unit between January 1995 and May 1996. Persons with SCI were considered eligible to participate in the study if they were at least 1 year post-injury, were neurocognitively intact and capable of completing self-report measures, and agreed to complete a packet of instruments. Three participants were excluded because they did not complete the questionnaire packet, but they did not differ demographically from those included in the following analyses.

Participants ranged in age from 19-73 years (mean = 45.54; SD = 13.05). Years post-injury ranged from 1-50 (mean = 17.67; SD = 11.90); 59% of the sample had quadriplegia and 41% had paraplegia. Over half the sample (60.9%) identified themselves as Caucasian. Thirty-nine percent were married, 26% were divorced, 24% were single and the remaining were widowed or cohabitating. Forty-two percent reported income less than \$20 000 per year and 46% reported annual income over \$40 000.

Procedure

Potential participants were approached by a research assistant and given a description of the study when they reported for their scheduled annual medical evaluation. Participation was voluntary and written consent was required. Following consent, each participant completed a packet of questionnaires, which included the new outcome measure and the validation instruments. Participants who were incapable of using a pencil (seven persons with quadriplegia) to complete the self-report measures responded orally to questions presented by the research assistant. This research protocol was approved by the appropriate Institutional Review Boards.

New outcome measure: spinal cord injury lifestyle scale (*SCILS*)

Description The SCILS is a measure of the frequency of health behavior performance in persons with SCI. It is a 25 item, self-report instrument designed to assess behaviors specific to SCI health maintenance and behaviors that promote general health for the avoidance of secondary impairments. Each item describes a different health behavior. Items were categorized *a priori* into five scales: cardiovascular (four items), genitourinary (four items), neuromusculoskeletal (eight items), skin (six items), and psychosocial (two items). The frequency with which each behavior is performed is rated using 'almost always', 'frequently', 'sometimes', 'rarely', and 'never'. Table 1 lists all items included in the SCILS. Behavior is rated for the previous 3 months.

A score is generated for each scale by totaling scores on each item on the scale using four for 'almost always', three for 'frequently', two for 'sometimes', one for 'rarely' and 0 for 'never'. One item (genitourinary #3) is reverse scored. A total score is comprised of the sum of the five scale scores. Higher scores on the SCILS are indicative of higher performance of behaviors that promote health in persons with SCI.

Development Item content of the SCILS was developed following a review of the literature on secondary impairments associated with SCI and the specific behaviors recommended to prevent their occurrence.^{20–27} Other items were generated from the literature and available assessment instruments on behaviors associated with risk reduction and health promotion in general.²⁸ Clinicians with SCI expertise (physicians, physician assistants, nurses, psychologists, physical therapists) also generated items describing health behaviors important for SCI management. A total of 47 items were created initially.

Item elimination Item elimination for the SCILS was conducted using standard content validation procedures. Persons with SCI and expert clinicians reviewed the initial version of the SCILS for item clarity and content. Five items were eliminated using this strategy. Empirical item elimination strategies included calculating item-total correlations (the Pearson correlation between an item and the sum of the remaining items in the scale without the item) for each *a priori* subscale. Items with item-total subscale correlations of less than |0.25| in magnitude were eliminated. This resulted in a final set of 25 items to comprise the SCILS used in the current reliability and validity analyses.

Validation criteria (standardized instruments)

There are difficulties in validating a measure for which no known standard is available. The following standardized instruments were selected that measure constructs other than health behavior, such as functional independence and psychological distress in the SCI population. Strong associations between the

Table 1 Spinal cord injury lifestyl	le scale
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Item	mean	SD
Cardiovascular		
1. I avoid smoking cigarettes.	3.07	1.44
2. I limit the amount of fat and cholesterol in my diet (for example, I limit red meats,	2.26	1.27
dairy products).		
3. I am aware of and try to reduce my risk for heart disease.	2.78	1.91
4. I monitor my blood pressure on a regular basis.	1.50	1.28
Genitourinary		
1. I use an intermittent catheterization program and stick to the recommended schedule.	1.72	1.67
2. I change my catheters as often as I have been directed to.	3.22	1.40
3. I have episodes of bladder incontinence.*	2.28	1.36
4. I use a rectal suppository as part of my regular bowel program.	1.52	1.72
Neuromusculoskeletal		
1. I do range of motion exercises daily to keep my joints flexible.	2.22	1.33
2. I do exercises that enhance my muscle strength (for example, weight training)	2.09	1.40
at least 3 times a week. 3. My muscle strengthening exercises are monitored by a therapist at least once a year.	1.70	1.65
4. I allow my shoulder joints to rest when I am having pain from overusing them.	2.57	1.41
5. I do activities which put weight on the bones in my legs to help increase bone density about	1.70	1.66
3 times a week (for example, use standing frame).	1.70	1.00
6. I pay attention to the position my body is in when I am in my wheelchair.	3.50	0.96
7. I pay attention to the position my body is in when I am sleeping.	3.24	1.18
8. If I noticed the beginning of a contracture (a joint that is 'freezing up'),	1.98	1.69
I would know exactly what to do.		
Skin	2.00	1.24
1. I check my skin to look for any areas of redness or breakdown.	2.80	1.34
2. I do some type of pressure relief every 30 minutes any time I am in my chair or driving.	2.96	1.33
3. I am careful not to bump my legs, feet, or buttocks when doing transfers.	3.24	1.14
4. I wear something on my feet when I am out of bed (for example, shoes or foam boots).	3.48	0.91
5. I am careful when handling hot liquids by not carrying them in my lap.	3.50	0.96
6. I am aware of the condition of my wheelchair cushion.	3.63	0.80
7. I am aware of the condition and repair needs of my wheelchair.	3.74	0.71
Psychosocial		
1. I am able to get around in my house (my house is wheelchair accessible).	3.61	0.71
2. I am with or talk to other people at least once a day.	3.87	0.45

Means and Standard Deviations for Items. (n=46) *This item is reverse scored. Range of possible score is 0-4 for each item. Lower scores are indicative of more frequent health behavior

SCILS and these measures were not anticipated. Clinicians' rating scales, created for this study, were expected to be more closely related to participants' reports of health behavior.

Functional independence measure (FIM) The FIM²⁹ is a widely used, standardized, 18-item instrument to assess functional status. SCI patient and staff ratings on the FIM are highly correlated and self-report on this measure has been suggested as a valid measure of functional independence.³⁰ Summed scores range from 18 (complete dependence on another person) to 126 (complete independence in functioning).

Brief symptom inventory (BSI) The BSI³¹ is a 53-item self-report measure designed to assess symptoms of psychological distress during the previous 7 days. Each

item of the BSI is rated on a 5-point scale, from 'not at all' (0) to 'completely' (4). For this study, two subscales were used: anxiety (six items) and depression (six items). Internal consistency and test-retest reliability are strong for each subscale.³¹ Normative data are available for SCI populations.³² Scores were determined by totaling the responses for the items on each subscale.

Impact of event scale (IES) The IES³³ is a 15-item self-report measure that assesses current degree of impact experienced in response to a stressful life event, in this case, SCI. Participants were asked to indicate how frequently each item had been true with respect to their SCI in the 7 days preceding the assessment. Responses were made using 4-point scales, from 'not at all true' to 'often true' (scores corresponding to 0, 1, 3, 5). The IES has two subscales, Avoidance (eight items,

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0-40 range of scores) and Intrusion (seven items, 0-35 range of scores), composed of mutually exclusive items. Sample items of the Avoidance scale include 'I stay away from reminders of it', and 'I try not to think about it'. Examples of items in the Intrusion subscale include 'I think about it' when I don't mean to', and 'I have dreams about it'. Higher scores correspond to greater degree of impact of the event. The IES has adequate reliability (Cronbach's $\alpha = 0.78$ for Intrusion and 0.82 for Avoidance).³³

Beck depression inventory (BDI) The Beck Depression Inventory (BDI)³⁴ is a 21-item self-administered questionnaire that assesses severity of depressive symptoms. Each item of the BDI is rated on a 4-point scale (0-3). Reliability and validity of the measure are well established. Items are clinically derived, reliable and valid.³⁵ Internal consistency assessments have been high ($\alpha > 0.90$) in most evaluations.³⁶ Scores can range from 0-63.

Validation criteria (study-specific measures)

Clinician and self-assessment of overall health behavior and functioning The clinician assessment and selfassessment of health are two overall rating questions asked of clinicians and participants. The first question assesses health behavior participation, rated from 0 'not at all' to six 'completely': 'Overall, to what extent do you (does the patient) participate in activities or

Table 2 Secondary impairments

Cardiovascular

swelling in legs and/or feet blood clots rapid onset of fatigue when pushing wheelchair chest pain heart attack diagnosed with heart disease autonomic dysreflexia high blood pressure low blood pressure blood pooling in legs and/or feet

Skin

skin scrapes mild pressure sore chronic pressure sore surgery to correct pressure sore

Neuromusculoskeletal

shoulder pain back pain leg pain spasticity that interferes with sleep spasticity that interferes with mobility spasticity that interferes with daily activities heterotopic ossification ('H.O.') broken bones below level of injury contractures ('frozen' hip, knee, ankle joints) BEHAVIORS that keep you (him) healthy? The second question assesses for an overall rating of independence in functioning, scored from 0 to 3: 'Overall, would you say your (the patient's) ability to INDEPENDENTLY engage in desired activities such as work, recreation, or daily living is 'poor', 'fair', 'good', or 'excellent'? The rating clinicians were those who were most knowledgeable about the participant and included the physician assistant who performed the physical examination, the primary nurse, and the physical therapist. Internal consistency estimates calculated for each type of clinician ranged from 0.77-0.79.

Secondary impairments checklist A list of 38 SCIrelated secondary impairments was generated using the existing literature.^{37,38} From this list, participants were asked to identify the impairments they had now, or had experienced within the past 12 months ('current'). Participants also were asked to identify secondary impairments they had ever experienced ('lifetime'). Internal consistency estimates were acceptable (current impairments, $\alpha = 0.80$; lifetime impairments, $\alpha = 0.75$). The impairments used in the Checklist are listed in Table 2.

Statistical analyses

Analyses were conducted in several steps, using SPSS/ $PC + .^{39}$ First, descriptive statistics were calculated for the 25 items, *a priori* subscales, and total SCILS score.

Genitourinary

frequent urinary tract infections frequent urinary incontinence kidney or bladder stones epididymitis frequent bowel accidents bowel impaction hemorrhoids rectal prolapse

Psychosocial

depression alcohol overuse prescription drug overuse 'street' drug use isolation

Other

hospitalization for medical problem (other than annual check-up) pneumonia Next, psychometric properties of the new measure were examined. Reliability was estimated using Cronbach's α to determine internal consistency of the *a priori* subscales and of all items contained on the SCILS. Validity was examined by calculating Pearson r correlation coefficients between the SCILS total score and each criterion measure. Finally, Student's *t*-tests assessed possible associations between SCILS total scores and demographic variables (eg, between Caucasians and ethnic minorities and between persons with paraplegia and quadriplegia).

Results

Means and standard deviations of the SCILS

Specific items on the SCILS, in addition to the mean and standard deviation for each are listed in Table 1. Means, standard deviations, and ranges for scores on the *a priori* subscales and for the total SCILS score are presented in Table 3.

Table 4 contains descriptive statistics for the criterion measures and Pearson correlation coeffi-

cients between these measurements and the SCILS. Normative data for SCI populations are presented for comparison with the current sample on the BSI,³³ FIM,⁴⁰ and BDI.⁴¹ Comparative SCI data are not available for the IES.

SCILS reliability

Cronbach's α coefficient represents a conservative lower bound estimate of a measure's reliability.⁴² Alpha of 0.50 and above is considered acceptable⁴³ although Nunnally⁴⁴ recommends α levels of at least 0.70. Cronbach's α for the SCILS was 0.81, which suggests that the items are related and measure a unitary construct. Alpha coefficients for each subscale are listed in Table 3. Table 3 also contains correlations between each SCILS subscale score and total SCILS score.

SCILS construct validity

Discriminant validity To demonstrate discriminant validity, the SCILS should be unrelated to scores on tests that measure constructs other than health

Table 3 SCILS descriptive statistics, subscale with total score correlations and estimates of internal consistency reliability

Subscale			Correlation			
	#items	Mean	SD	Range	w/Total Score	alpha
cardiovascular	4	9.61	3.84	1 - 16	0.40*	0.73
genitourinary	4	8.74	3.57	0 - 14	0.42*	0.32
neuromusculoskeletal	8	18.98	6.72	3 - 32	0.88**	0.75
skin	7	23.35	5.31	1 - 28	0.79**	0.86
psychosocial	2	7.49	0.91	4 - 8	0.10 ns	0.31
Total score	25	68.15	13.28	29-92		0.81

*two-tailed P<0.01 **two-tailed P<0.001

 Table 4
 Associations between SCILS total score and validation criteria, norms for SCI population and sample means and standard deviations

Validation measure	Pearson r	SCI mean (SD)	Sample mean (SD)
Beck depression inventory	-0.17	9.10 (8.8)	7.37 (6.41)
Brief symptom inventory			
Depression	-0.13	0.57 (0.70)	0.47 (0.50)
Anxiety	-0.16	0.53 (0.59)	0.37 (0.47)
Impact of events scale			
Intrusion	-0.16		
Avoidance	0.10		
Functional independence measure	-0.06	99.4 (25)	104.1 (22.58)
Secondary impairments			
Current	0.04		6.91 (5.22)
Lifetime	0.08		8.15 (5.04)
Clinician assessment of overall health behavior			
Physician assistant	0.41*		
Physical therapist	0.30		
Nurse	-0.18		
Self-assessment of overall health behavior	0.51**		

*P<0.05; **P<0.005

behavior.⁴⁵ Discriminant validity was assessed by correlating SCILS total scores with the standardized criterion measures of depression, anxiety, 'impact' of SCI, and functional independence as assessed by BDI, BSI, IES and FIM, respectively. These relationships are presented in Table 4. The SCILS score was not associated with the constructs of depression or anxiety as measured by the BDI or the BSI. SCILS scores were not related to the Intrusion or Avoidance subscales of the IES. SCILS scores were not correlated with the extent to which participants reported their ability to perform functional tasks listed on the FIM.

Convergent validity Convergent validity is established by showing that a measure is related to other measures that assess the same construct.⁴⁶ In this case, Pearson correlations were calculated between SCILS score and overall self-ratings of health behavior provided by participants, and between SCILS score and clinician's ratings of participants' health behavior. Participants' self-ratings were highly correlated with total SCILS score (r=0.51, P=0.004). Similarly, physician assistant's ratings of participants' health behavior were significantly correlated with SCILS score (r = 0.41, P = 0.02). Physical therapists' ratings were not related to SCILS score, although there was a trend in this direction (r = 0.30, P = 0.13). Nurses' overall ratings of participant's health behavior were not associated with SCILS scores (r = -0.18, P = 0.39). Table 4 lists these relationships.

Criterion-based validity

Criterion-based validity was assessed concurrently using the SCILS and participant reports of the number of their current and past secondary impairments. A relationship was expected between the SCILS and the number of secondary impairments, however, this was not supported (r=0.04, 'current' impairments and r=0.08, 'lifetime' impairments; see Table 4).

SCILS and demographic variables

Student's *t*-tests of the SCILS total score did not differentiate between Caucasian and ethnic minority status, time post-injury or type of injury (ie, paraplegia or quadriplegia). SCILS total score also was unrelated to reported income level and to age. While Caucasians scored slightly lower than ethnic minorities on the SCILS (65.8 vs 71.8, respectively) the difference was not statistically reliable (t = 1.51, P = 0.14).

Discussion

The present study describes the development and initial refinement of a new measure for the assessment of health behavior in persons with SCI. To our knowledge, this is the first attempt to develop an empirically validated instrument to assess SCI-related health behavior in this population. An instrument to measure this construct is important for the evaluation of current clinical practices and development of future interventions to prevent secondary impairments related to SCI.

Evidence for the psychometric properties of the 25item, self-report measure is encouraging. The SCILS is internally consistent ($\alpha = 0.81$), which suggests that it is a cohesive measure of health behavior performance for persons with SCI. Further, there is preliminary support for the new measure's construct validity. First, as a construct, health behavior should not significantly overlap with unrelated constructs of psychological distress or functional independence. Discriminant construct validity of the SCILS is evidenced by minimal associations between the new self-report measure and self-report measures of other constructs (eg, depression, anxiety, cognitive intrusions/avoidance, and functional independence). While it is not possible to 'prove' null hypotheses, the results are still encouraging. Second, convergent construct validity is suggested by the associations between SCILS scores and physician assistants' ratings, and between SCILS scores and participants' self-ratings of overall health behavior performance. Further, the SCILS does not appear to be contaminated by type of SCI (ie, paraplegia vs quadriplegia), ethnicity, years post-injury, SES or age.

Participants who engaged in more health behaviors were expected to have less SCI-related secondary impairments, but this relationship was not observed. There are several possible explanations for this finding. First, health behavior performance is assumed to prevent or significantly delay the development of secondary impairments; however, participant reports that rely on retrospective recall of secondary impairments and personal 'diagnoses' of current problems is not an ideal assessment strategy. Medical records review and/or clinician assessments might yield more accurate estimates of participants' past and current secondary impairments. The present study's failure to establish criterion-based validity also may be related to the inclusion of patients early in their 'career' of SCI management; some participants were only one year post-injury and may not have had enough time to develop secondary impairments. Finally, the current form of the SCILS does not include all potentially relevant health behaviors that might influence the onset of secondary impairments. Additional items, further refinement of the measure, and prospective investigations may establish more convincing evidence of the SCILS' ability to predict secondary impairments.

Because there is no criterion standard measure of health behavior unique to SCI, there is no clear path for construct validation of this new outcome measure. The most promising result from the present study is the strong relationship between clinicians' ratings of health behavior performance and SCILS scores, because clinician observations of health behavior participation conceptually are a close approximation of the construct that the SCILS is designed to measure. Clinicians (ie, physician assistants) who performed the history and physical examination rated

participants' overall health behavior in a direction and magnitude that was similar to participants' self-reports on the SCILS. In contrast, physical therapists' and nurses' ratings were not correlated with participants' SCILS scores. This pattern of relationships is highly plausible: that participants' reported health behavior is most associated with the opinions of health professionals who may have the most direct information about the participants' health. A medically focused examination performed by physician assistants may yield information that is more reflective of the extent to which a person with SCI engages in behaviors that will prevent or delay secondary impairments. Nurses and physical therapists typically focus on other content domains, including functional status and psychosocial concerns. Consequently, they would not be expected to have patient information that directly matches the data collected by physician assistants.

The SCILS appears to be a reasonable first step in the process of generating a validated outcome measure to assess health behavior in persons with SCI, but the study has several limitations. Most noteable is the relatively small sample size which was an unpredictable and unavoidable liability encountered due to personnel re-assignments. Because of the limited sample (and low statistical power), it is unclear whether the failure to detect some predicted associations was due to unstable estimates or that the relationships did not hold. With the small sample size, the extent of generalizability of the findings also is uncertain. Thus, refinement of the SCILS will be an iterative task, beginning first with replication in larger samples to provide more stable estimates of the associations between the SCILS and other constructs. Further testing should include 'known-groups' validation, in which the specificity of the SCILS is tested in other SCI populations (eg, in other clinical settings) and non-SCI populations. It also should be evaluated for its sensitivity to change following clinical interventions that alter health behavior performance.

Further item refinement may be necessary. Eight questions with item-total correlations (ie, each item correlated with the sum of the remaining 24 items) less than 0.25 could be eliminated from the current pool of 25 items, thus increasing the SCILS's internal consistency coefficient to $\alpha = 0.87$. Additionally, the current version of the SCILS may be improved by refining the subscale reliabilities (Table 3). While it is rare to observe high internal consistency with so few items, it is apparent that the genitourinary and psychosocial subscales require improvement or possible deletion. The two psychosocial items and three of the four genitourinary items are among the eight items that could be deleted by an item-total correlation criterion as described above, providing further evidence for the removal or refinement of these subscales. Conversely, items may need to be added to the SCILS. This could be accomplished by examining their conceptual fit in the SCILS and by assessing new items, bivariate relations with relevant criteria.

Health behaviors are known to prevent or significantly delay SCI-related secondary impairments such as pressure ulcers,²⁰ shoulder joint degeneration and pain,²¹ gastrointestinal problems,²² urinary tract infections,²³ coronary artery disease,²⁴ osteoporosis,²⁵ fracture²⁶ and spasticity.²⁷ The ability to influence the practice of these behaviors has obvious personal, economic, and health policy implications; however, an empirically validated measure is required before changes can be realized in any of these realms. The findings presented here suggest that the SCILS is a promising measure that could be used for this purpose. After further testing and development of the measure, the SCILS could be used to evaluate the effectiveness of clinical and educational efforts directed at influencing health behavior in persons with SCI, and to direct improvements in these health care services. Ultimately, interventions that result in increased health behavior can be identified, which in turn can yield health care cost reductions and enhanced quality of life in persons with SCI.

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