Potentially modifiable risk factors among veterans with spinal cord injury hospitalized for severe pressure ulcers: a descriptive study

Marylou Guihan¹, Charles H. Bombardier²

¹Edward Hines VA Medical Center, Hines, IL, USA, ²University of Washington, Seattle, Washington, USA

Context/objective: Pressure ulcers (PrUs) are a serious, costly and potentially life-long complication of spinal cord injury (SCI). Co-morbid conditions increase PrU risk, adding to the health behavior challenges faced by people with SCI. Little is known about medical co-morbidities, health beliefs, risk, protective behaviors, and readiness to improve skin care behaviors in people with SCI. This study describes the potentially modifiable medical and behavioral risk factors among veterans with SCI and severe (Stage III/IV) PrUs.

Design: Cross-sectional observational design.

Setting: 6 VA SCI Centers.

Participants: Convenience sample from a larger intervention study of 148 veterans hospitalized for PrUs.

Interventions: Not applicable.

Outcome measures: Knowledge, PrU risk, skin protective behaviors, health beliefs, and practices, health locus of control, skin worsening.

Results: Most ulcers were stage IV (73%) and about half had 2+ PrUs. Participants reported a mean of 6.7 co-morbid conditions (respiratory, gastrointestinal, renal disease/urinary tract infection, autonomic dysreflexia, diabetes, bowel/bladder incontinence). Potential intervention opportunities include proactive assistance with management of multiple chronic conditions, substance abuse, nutrition, adherence to skin protective behaviors, readiness to change, and access to resources. Overall knowledge about PrUs was low, especially for how to prevent PrUs and what to do if skin breakdown occurs.

Conclusion: Future research should address whether comprehensive models that include patient self-management, decision support and health care system, and proactive behavior change assistance for patients help reduce PrU incidence and recurrence in persons with SCI.

Trial Registration: <http://clinicaltrials.gov/ct2/show/NCT00105859>

Keywords: Spinal cord injuries, Pressure ulcers, Veterans, Paraplegia, Tetraplegia, Chronic care model, Salzburg scale

Introduction

Pressure ulcers (PrUs) are a common and costly complication of spinal cord injury or disorder (SCI/D). A 1968 study found that half of the individuals with tetraplegia and about a third of those with paraplegia required hospitalization for treatment of PrUs.¹ Recent studies show little change in these numbers.² In fact, there is evidence that PrU incidence is increasing in the current era,³ especially among those 10 years or more post-injury. The reported prevalence rates of PrUs in individuals with SCI residing in the community have ranged from 17 to 33%, usually within a 1-year reporting period.⁴⁻⁶

In a recent survey of veterans with SCI, approximately 36% of respondents reported having PrUs during the previous year.⁷ PrUs have become the second most frequent cause of rehospitalization after an SCI,⁸ with estimated annual costs of about \$1.4 billion in the United States.⁶

The cause of PrUs is multi-factorial, including biological, behavioral, and social components. Studies of medical therapies⁹ and non-modifiable risk factors¹⁰ far exceed those of behavioral treatments and modifiable risk factors. With the exception of daily skin checks and smoking,^{11,12} evidence linking behavior to PrU outcomes is limited. Nevertheless, the importance of patient behavior has high face validity and we continue to teach that patient skin care behavior and

Correspondence to: Marylou Guihan, Edward Hines Jr. VA Hospital, Bldg 1, Room D 306 (151H); Hines, IL 60141, USA. Email: marylou.guihan@va.gov

other health-related behaviors are important (“Yes You Can”).¹³ Therefore, more research is needed to identify modifiable risk factors and to gather information that can guide the development of more effective interventions.

This is a cross-sectional descriptive study of veterans with SCI who were hospitalized for severe PrUs. We created an assessment designed to explore characteristics of study participants from different theoretical perspectives. The primary purpose of this study was to describe factors thought to be related to participants’ ability to self-manage their skin to prevent PrUs. These factors included the overall number and type of co-morbid medical conditions that the patient has to manage and their knowledge relevant to PrUs. Based on the *Transtheoretical Stages of Change model*,¹⁴ we were interested in measuring not only self-reported adherence to clinical practice guideline-recommended skin management behaviors¹⁵ but also readiness to improve these behaviors. On the basis of the *Health Belief Model* (HBM),¹⁶ we wanted to measure beliefs about perceptions regarding the seriousness of PrUs, their susceptibility to recurrence and the efficacy of PrU preventive behaviors. Finally, it seemed worthwhile to describe the sample in terms of health locus of control beliefs.¹⁷ Our primary hypotheses were that those with a high number of medical co-morbidities would report poorer PrU-related knowledge, lower rates of adherence, less adaptive health beliefs, and less internal locus of control compared with those with fewer co-morbid medical conditions with which to cope. We expected that this multifaceted assessment would reveal several logical vectors for future research and potential interventions.

Methods

Study design

Data were collected from patients at six Veteran Affairs (VA) SCI centers. All subjects were enrolled in a prospective randomized controlled trial (RCT) that examined the efficacy of a self-management education and telephone counseling intervention to prevent PrU recurrence.¹⁸

Eligibility criteria

To participate in the intervention study, subjects had to have a traumatic SCI of longer than 1 year in duration, be cognitively intact, age at least 18 years old and be hospitalized at one of the six participating VA SCI centers for the treatment of a stage III or IV pelvic PrU (defined as occurring over the sacrum, coccyx, trochanter, or ischium) also referred to as the “study ulcer” in the following text. Cognition was evaluated by medical record review or clinical judgment of the site principal investigators (all of whom were physicians).

Exclusion criteria included a terminal diagnosis, severe psychiatric co-morbidities (e.g. schizophrenia and other active psychoses) and hearing or cognitive impairments that would limit their ability to participate in the telephone counseling intervention.

Participants

The original sample for this study included 148 veterans with SCI and stage III or IV PrUs admitted to 6 VA SCI centers participated in the study. Our analyses excluded subjects who dropped out of the study ($n = 2$) or had incomplete data for any of the study forms ($n = 15$), resulting in a sample size of 131.

Human subjects review

The study received approval from all the participating institutional review boards at each VA Medical Center (VAMC) and affiliated universities when necessary.

Data collection procedures

Study enrollment began in November 2003 and follow-up ended in June 2005. Local study Site Coordinator (SC) conducted in-person interviews with all eligible subjects who consented to participate in the study to obtain demographic and clinical characteristics, ulcer history and study instruments. Data for these analyses were collected after hospital admission and prior to being randomized to the study intervention at the time of discharge to the community. The time reference for specific behaviors was prior to being admitted to the hospital for ulcer treatment.

Measures

Description of Instruments

Demographic and health information questionnaires

Demographics (age, race, ethnicity, marital status, and level of education), SCI information (age at onset of SCI, time since onset), and self-reported skin care behaviors prior to hospitalization were obtained via patient interview. Information on co-morbid conditions, PrU history (number and treatment), and ulcer characteristics was obtained from the subjects’ electronic medical records and verified by their primary care provider.

Injury severity

Level and severity of injury were obtained from medical record review.

Depression

Veterans are formally screened for depression during their annual evaluation and when admitted to the hospital. If either screen is positive, the primary care provider makes a referral to mental health for a full diagnostic

assessment. Research staff also screened subjects for depression using the Patient Health Questionnaire-9 (PHQ9). One subject was referred to mental health as a result of our screening. The percentages in the table reflect a medical diagnosis of depression.

Co-morbid conditions

Charlson Index Scores, a measure of co-morbid chronic illnesses, were calculated using VA administrative data for 2 years before the subject's admission into the study. The Charlson Index contains 17 categories of co-morbidity derived from ICD-9-CM diagnosis codes.^{19,20} The overall Charlson Score (which can range from 0 to 7) reflects the cumulative likelihood of 1-year mortality, so a higher score reflects a greater burden of illness.

PrU knowledge test

This 14-item survey assessed subject knowledge about known PrU risk factors, including PrU etiology, stages, skin inspection, weight shifts and turns, nutrition, wheelchair and bed support surfaces, and prevention and management strategies. The PrU knowledge test has been used in previous studies and has acceptable internal consistency (Cronbach's $\alpha = 0.72$).²¹ The knowledge test score is based on the number of correct responses for each item summed across all items and scores are reported as the percentage of the total points earned from correct responses, with higher scores indicating greater knowledge.

PrU risk assessment scale for individuals with paralysis

The Salzberg scale assesses PrU risk factors in the SCI population, for example, level of activity, level of mobility, complete SCI, urine incontinence or moisture, autonomic dysreflexia, pulmonary disease, and renal disease.¹⁶ Salzburg risk scores were calculated using subject self-report and confirmed by review of the subject's electronic medical record. Higher scores reflect an increased risk of developing PrUs.

Skin behavior checklist

The Skin Behavior Checklist is a list of guideline recommended skin care behaviors. Subjects were asked to rate their readiness to follow each of the eight guideline-recommended skin care behaviors on a scale that ranged from 1 (Not ready to improve) to 10 ("I already follow this guideline completely"). The readiness ruler concept uses a numerical analog scale and was adapted from research in other health care behaviors that indicate that readiness scales outperform longer questionnaires in terms of predicting behavioral intentions.²²

Health beliefs and practices

The HBM¹⁷ describes the relation between one's beliefs about their health and their health-related behaviors, especially regarding the prevention of disease.²³ We adapted the standard HBM questionnaire item content to address skin management issues including: (i) perceived susceptibility to PrUs, (ii) perceived severity of PrUs, (iii) perceived effectiveness of practices for preventing PrUs, and (iv) perceived barriers to healthy skin care.

Multidimensional health locus of control scale²⁴

The scale was used to measure the extent to which subjects believed that their PrU-related outcomes were controlled by internal vs. powerful other vs. chance forces.

Data analysis

We calculated descriptive statistics (means and percentages) to describe the sample in terms of the overall rates of co-morbidities and PrU risk factors as well as skin care-related knowledge, skin care behaviors, skin care beliefs, skin care barriers, and locus of control. For the analyses presented here, baseline (pre-intervention) scores were used. In addition, we examined whether skin care knowledge, behaviors, beliefs, and locus of control differed between individuals with of high vs. low burden of co-morbid medical illnesses.

High vs. low co-morbidities

We used the Charlson Index to divide the sample into low vs. high medical co-morbidity based on a median split: (i) low co-morbidity (Charlson ≤ 2) and (ii) high co-morbidity (Charlson ≥ 3).

For continuous variables, *t*-tests were used to determine whether there were significant differences between the two groups. For categorical variables, χ^2 tests were used to compare the two groups. All statistical analyses were conducted using SAS version 9.2 (SAS Institute, Cary, NC, USA).

Results

Demographic, SCI, and PrU characteristics

The mean age of study subjects was 55.9 years (s.d. = 9.9, range = 23–89 years), with those in the high co-morbidity group being significantly older than those in the low co-morbidity group (58.5 vs. 53.9; see Table 1). The groups were similar on other medical and demographic characteristics. Subjects had been injured for an average of 22.2 years prior to enrollment (s.d. = 12.8, range = 1–52 years), nearly 35% were non-White race and 87.8% had a high-school degree or some college. The most common causes of SCI included motor vehicle crash (40%), gunshot wound (22%), and

Table 1 Sample demographic, spinal cord, and ulcer characteristics (n = 131)

	Total	Low co-morbidity	High co-morbidity	P value
Mean age (years)	55.9 (s.d. = 9.9)	53.9 (s.d. = 9.9)	58.5 (s.d. = 9.4)	0.007
Percentage of male	97.7	95.8	100.0	0.25
Percentage of white race	64.9	63.9	66.1	0.79
Mean years since injury	22.2 (s.d. = 12.8)	20.4 (s.d. = 11.9)	24.4 (s.d. = 13.5)	0.07
Percentage with high school or college education	87.8	84.7	91.5	0.32
Percentage of Paraplegia	68.7	59.7	80.0	0.02
Percentage of ASIA A	73.3	76.4	69.5	0.37
Percentage of Stage 4 ulcer	73.3	69.4	78.0	0.27
Number of current pressure ulcers				
1	62.6	62.5	62.7	1.00
2	22.1	22.2	22.0	
3	9.9	9.7	10.2	
4+	5.3	5.6	5.1	
Size of study ulcer (cm ²)	48.9 (s.d. = 57.3)	49.9 (s.d. = 53.6)	45.3 (s.d. = 60.6)	0.88

fall or diving accident (19%). Just over two-thirds of the sample had paraplegia and most (73.3%) had a complete SCI (ASIA A).

The study ulcer for sample participants was most frequently categorized as stage IV in 73.3%, 34% of these ulcers were infected, and 40% of these ulcers had undermining of adjacent tissue. The mean size of the largest study ulcer was 48.9 cm² (s.d. = 57.3 cm) and the median ulcer size was 26.0 cm². Consistent with the notion that PrUs represent a chronic or recurrent condition, subjects reported having had the study ulcer for an average of almost a year (range < 1–13 years) before being admitted for treatment. In addition,

we found that the study ulcer was the first severe (stage III/IV) ulcer for only 14% of study patients. The mean number of prior PrUs per subject was 1.8. Subjects had on average 2.2 prior PrU surgeries (range = 0–20). About 37% of study subjects had more than one PrU currently; 22% had two, and 15% had three or more concurrent PrUs.

Co-morbid medical conditions

PrUs were rarely the only medical condition with which the subject had to cope. As shown in Table 2, study subjects reported a mean of 6.7 co-morbid conditions in addition to their SCI and PrUs. Notable co-morbid

Table 2 Co-morbid medical conditions (n = 131)

Mean number of diagnoses per patient = 6.7 (range = 2–12)

Patients with at least 1 diagnosis per category	Overall percentage of present at admission	Low co-morbidity	High co-morbidity	P value
Skin/pressure ulcer complications (e.g. cellulitis, psoriasis, wound dehiscence, osteomyelitis, and undermining)	96.2	94.4	98.3	0.25
Neurological (e.g. dementia, Parkinson's disease, spasticity, stroke, transient ischemic attack, and syncope)	70.2	73.6	66.1	0.39
Trauma (e.g. drug reaction, fall, and orthopedic injury)	62.6	43.0	30.5	0.14
Cardiac (e.g. angina, heart disease, cardiac arrest, hypertension, and myocardial infarction)	58.0	37.5	52.5	0.08
Gastrointestinal (e.g. gastroenteritis, C difficile, and impaction)	51.2	50.0	52.5	0.71
Genitourinary (e.g. renal failure, renal retention, dialysis, UTI, and GU* cancer)	49.6	45.8	54.2	0.34
Hematologic (e.g. anemia, hematologic cancer, and sickle cell)	48.9	45.8	52.5	0.44
Musculoskeletal (e.g. arthritis and joint/soft tissue pain)	48.1	52.8	42.4	0.23
Respiratory (e.g. actual respiratory failure, lung cancer, pneumonia, and upper respiratory infection)	44.3	61.1	64.4	0.69
Endocrine (e.g. diabetes and hypoglycemia)	37.4	20.8	57.6	0.0001
Psychological (e.g. psychosis, anxiety, depression, and schizophrenia)	27.5	27.2	27.1	0.93
Vascular (e.g. arterial occlusion, deep vein thrombosis, Peripheral vascular disease, and pulmonary embolism)	13.7	6.9	22.0	0.013
Tubes (e.g. foley catheter and suprapubic)	13.5	22.0	5.0	0.79

*Genitourinary

conditions that might involve the need to adhere to additional medical treatments or to make lifestyle changes include cardiac disease (26.1% had hypertension), endocrine disorders (32.1% had diabetes), genitourinary disorders (28.9% had a urinary tract infection UTI), and psychological disorders (27.5% had a medical diagnosis of depression).

Salzburg risk assessment

Sample characteristics for the items on the Salzburg PrU risk assessment are shown in Table 3. The mean Salzburg score for the overall sample was 10.1 (range = 4–19), which falls within the highest risk category (“very high”) based on the original validation sample for this measure. More than a third (34.4%) were current smokers, 57.8% had low protein levels, and 57.3% had evidence of anemia. Urinary incontinence or constant moisture was reported in 19.1% of the sample.

Significant differences between high and low co-morbidity groups included level of activity, higher percentage older than 65 (27.1 vs. 9.7, respectively), rates of diabetes (55.9 vs. 12.5), renal (15.3 vs. 2.8), and vascular disease (22.0 vs. 6.9). The only Salzburg item on which the low co-morbidity group score was higher was autonomic dysreflexia/spasticity (55.6 vs. 37.3%).

PrU knowledge

The mean percent of correct items on the PrU knowledge test for the sample was 73.4% (see Table 4), with no significant differences observed between the high- and low-co-morbidity groups. Questions for which subjects’ knowledge was especially poor included lack of familiarity with the four stages of PrUs (correct = 57.9%) and nutrition (correct = 59.9%). Approximately one-third of the sample was unable to correctly identify ulcer location or etiology, prevention strategies, or recommended frequency of pressure relief (62.2%). The correlation between the knowledge score and a history of previous ulcers was not significant ($r = 0.08$; $P = 0.32$).

Skin care behaviors

As shown in Table 5, only 51.2% of the sample reported bathing daily. With respect to urinary incontinence, about 30% of participants reported daily, weekly, or monthly problems. More participants reported bowel (than bladder) incontinence, with monthly incontinence reported most frequently (23.7%). Subjects reported sitting in their wheelchair or in bed for an average of 10 hours per day, with an average of 4 pressure reliefs per hour.

Table 3 Salzburg pressure ulcer risk factors ($n = 131$)

	Total	Low co-morbidity	High co-morbidity	P value
Mean total score	10.1	10.0	10.3	0.61
(s.d.)	(3.0)	(3.1)	(2.9)	
Range	4–19	4–19	4–18	
Scale items	(%)	(%)	(%)	
Level of activity				
Wheelchair	57.3	48.6	67.8	0.03
Bed	42.3	51.4	32.2	0.03
Mobility				
Full	3.0	2.78	3.39	1.00
Limited	80.9	79.2	83.1	0.6
Immobile	16.0	18.1	13.6	0.5
Complete SCI	60.1	63.9	57.6	0.5
Urinary incontinence/constantly moist	19.1	16.7	22.0	0.4
Autonomic dysreflexia/severe spasticity	47.3	55.6	37.3	0.04
Age (years)				
<34	3.1	5.6	0.0	0.1
35–64	79.4	84.7	72.9	0.1
>65	17.6	9.7	27.1	0.01
Tobacco use/smoking				
Never	17.6	19.4	15.3	0.5
Former	48.1	45.8	50.9	0.5
Current	34.4	34.7	33.9	0.9
Pulmonary disease	12.2	13.9	10.2	0.5
Cardiac disease or abnormal electrocardiogram	16.0	11.1	22.0	0.09
Diabetes or glucose > 110 mg/dl	32.1	12.5	55.9	<0.0001
Renal disease	8.4	2.8	15.3	0.02
Impaired cognitive function	5.3	4.2	6.8	0.7
Admitted from nursing home or hospital	29.8	30.6	28.8	0.8
Albumin < 3.4 or total protein < 6.4	57.8	51.4	67.8	0.07
Hematocrit < 36% or HGB* < 12.0	57.3	51.4	64.4	0.1

*Hemoglobin

Table 4 Pressure ulcer knowledge test (n = 131)

Knowledge test items (in rank order)	Correct answers	Low co-morbidity	High co-morbidity	P value
Mean score (across all items)	73.4%	75.0%	72.2%	0.30
Percentage of correct answers	%	%	%	
Wheelchair age	98.9	98.6	99.1	0.68
Prevention strategies	92.4	93.8	90.7	0.50
Wheelchair cushion replacement	91.1	89.4	93.2	0.43
Type of cushion	86.4	85.2	87.9	0.61
Steps to take if skin breakdown occurs	78.6	81.9	74.6	0.31
Frequency of pressure relief	72.1	66.0	80.0	0.07
Ulcer etiology	68.4	68.8	68.0	0.80
Prevention strategies	66.1	66.5	65.7	0.84
Frequency of skin inspection	62.2	66.0	57.6	0.33
Ulcer location	62.3	64.5	59.7	0.34
Nutrition items	59.9	60.8	58.9	0.73
Ulcer stages	57.9	63.9	50.6	0.07

Table 5 Frequency of self-reported skin care behaviors (n = 131)

Frequency of skin care behaviors	Never (%)	Daily (%)	Weekly (%)	Monthly (%)
Bathing	—	51.2	47.3	<2
Urinary incontinence	71	9.2	8.4	10.7
Bowel incontinence	64	5.3	6.9	23.7
Mean hours of sitting per day			10.2 (s.d. = 6.0)	
Mean number of pressure reliefs per hour of wheelchair sitting			4.0 (s.d. = 5.1)	

Adherence and readiness to change skin care behaviors

As shown in Table 6, subjects are most likely to report that they do not use street drugs (89.3%) or drink alcohol in excess (87.8%). Large proportions of the sample reported that they did not follow commonly recommended skin care behavior guidelines. For example, only 42.8% reported that they contacted the doctor or nurse within a day or two of when they notice a new or worsening skin breakdown and only 55% perform pressure reliefs every 15 minutes. Only 16% of subjects reported having a worn-out wheelchair cushion.

Among those not currently following the guidelines, the majority reported that they are ready to or trying

to change in the areas of skin checks, pressure reliefs, cushion care, and seeking medical help quickly. In contrast, only about half of those not following the guidelines reported that they are ready to or trying to change their behaviors in the areas of alcohol use, drug use, tobacco use, or turning every 2–4 hours when in bed.

A large proportion of the sample reported that they “never” follow common dietary advice such as reading nutrition labels on foods (44%), choosing a diet low in fat (48%), limiting sugar (34%), eating 6–11 daily servings of bread, cereal, rice, or pasta (59%) (Table 7). Subjects reported better adherence to recommendations regarding consumption of fruits, vegetables, and meat or other protein sources.

Table 6 Adherence to recommended skin care behaviors and readiness to change (n = 131)

Skin care guideline recommended behavior	Adherence to and readiness to change skin care behaviors				
	Percent following guideline	Percent not ready to change	Percent unsure	Percent ready to change	Percent trying to change
No excessive alcohol use	89.3	3.0	1.5	2.3	3.8
No “street” drug use	87.8	6.1	1.5	1.5	3.5
Good cushion care	69.5	1.5	2.3	10.7	16.0
No tobacco use	64.9	11.5	5.3	9.2	9.2
Turn in bed every 2–4 hours	64.9	10.7	7.6	9.2	7.6
Daily skin checks	64.1	6.1	3.8	15.3	10.7
Pressure reliefs every 15 minutes	55.0	6.9	6.1	20.6	10.7
Seeks medical help quickly	42.8	11.5	5.3	22.9	17.6

Table 7 Other pressure ulcer risk behaviors (n = 131)

Risk behaviors	Total (%)	Low co-morbidity	High co-morbidity	P value
Tobacco use				
Current smoker	33.6	31.9	35.6	0.66
Previous smoker	51.2	50.0	52.5	0.77
Drinks alcohol				
4+ times per week	4.6	5.6	3.4	0.69
2-3 times per week	6.1	5.6	6.8	1.00
2-4 times per month	10.7	8.3	13.6	0.34
Monthly	23.7	25.0	22.0	0.69
Never	55.0	55.6	54.2	0.88
Typical number of drinks per day				
Don't drink alcohol	55.7	55.6	55.9	0.97
1-2	25.2	25.0	25.4	0.96
3-4	16.0	16.7	15.3	0.83
5+	3.1	2.8	3.4	1.0
Nutrition				
Percentage of often or frequently				
(a) Eat only 2-3 servings from the meat, poultry, fish, dried beans, eggs, and nuts group each day?	93.1	95.8	89.8	
(b) Eat 3-5 servings of vegetables each day?	89.3	87.5	91.5	
(c) Eat breakfast?	89.0	90.3	93.2	
(d) Eat 2-4 servings of fruit each day?	85.5	83.3	88.2	
(e) Eat 2-3 servings of milk, yogurt, or cheese each day?	84.7	97.2	83.1	
(f) Limit sugar and foods containing sugars (sweets)?	61.4	55.6	73.0	
(g) Eat 6-11 servings of bread, cereal, rice, and pasta each day?	58.8	55.6	67.2	
(h) Choose a diet low in fat, saturated fat, and cholesterol?	48.1	44.4	52.5	
(i) Read labels to identify nutrients, fats and sodium content of packaged food?	43.5	38.9	49.2	

Health beliefs

The results for the health beliefs questions shown in Table 8 suggest a further opportunity for continued risk reduction efforts. About 92% of the sample believes that PrUs are serious and that they are at risk of recurrence (75%). Subjects overwhelmingly believe that they can prevent PrU development somewhat or completely. Nearly all subjects reported that the following skin care behaviors make “a lot” of difference in whether or not they develop a PrU: using a wheelchair cushion, daily skin checks, and weight shifts.

The major benefits associated with adherence to good skin care practices were preventing ulcers (83%), feeling better physically (75%), peace of mind, not worrying (71%), and satisfaction that “I am doing the right

thing by taking care of myself” (71%). The most frequently endorsed difficulties associated with following good skin care practices were: forgetting to do them (18%), they are too much trouble (13%), they take too much time (12%), lack of help (10%), and they are unpleasant (10%).

Locus of control

Table 9 shows the results of locus of control scale and items. Overall, scores on internal, powerful other, and chance are similar to findings in other healthy and medically ill populations. There was a non-significant trend for people with higher medical co-morbidity scoring higher on the chance subscale compared with those with a low medical co-morbidity score. The item level

Table 8 Skin care health beliefs (n = 131)

Health beliefs	Mean		Low co-morbidity		High co-morbidity		P value
	%	N	%	N	%	N	
Percentage of somewhat or completely agree							
Using a wheelchair cushion prevents PrUs	100	131	100	72	100	59	1.00
Weight shifts prevent PrUs	98.47	129	100	72	96.61	57	0.20
Daily skin checks prevent PrUs	97.71	128	98.31	58	97.22	70	1.00
I can prevent pressure ulcers	95.42	125	95.77	68	96.61	57	1.00
Limiting sitting time prevents PrUs	92.37	121	95.83	69	88.14	52	0.13
Pressure ulcers are serious	92.31	121	97.18	69	88.14	52	0.078
I am at risk of PrU recurrence	74.87	98	68.06	49	83.05	49	0.049
I have difficulty following good skin care practices	38.17	50	43.06	31	32.20	19	0.33

Table 9 Locus of control (n = 131)

Subscale scores	Total		Low co-morbidity		High co-morbidity		P value
Mean internal	28.11	5.24	28.07	4.57	28.15	6.05	0.93
Mean powerful other	23.14	5.84	22.72	5.61	24.64	6.64	0.38
Mean chance	18.06	6.48	17.11	6.60	19.22	6.18	0.062
Percentage of slightly, moderately, or completely agree	%		%		%		%
The main thing which affects your health is what you yourself do	89.31	117	87.50	63	91.53	54	0.46
If you take care of yourself, you can avoid illness	79.39	104	80.56	58	77.97	46	0.72
You are in control of your health	78.63	103	77.78	56	79.66	47	0.79
If you take the right actions, you can stay healthy	77.86	102	76.39	55	79.66	47	0.65
If you get sick, it is your own behavior which determines how soon you get well again	76.34	100	73.61	53	79.66	47	0.42
When you recover from an illness, it's usually because other people (e.g. doctors, nurses, and family friends) have been taking good care of you	69.41	97	69.44	50	69.49	41	1.00
Having regular contact with your physician is the best way for you to avoid illness	63.36	83	58.33	48	69.49	41	0.19
Whenever you do not feel well, you should consult a medically trained professional	57.25	75	56.94	41	57.63	34	0.94
Your family has a lot to do with your becoming sick or staying healthy	44.27	58	48.61	35	39.98	23	0.27
If it is meant to be, you will stay healthy	41.22	54	33.33	24	50.85	30	0.043
Most things that affect your health happen to you by accident	40.46	53	36.11	23	45.76	27	0.26
No matter what you do, if you are going to get sick, you will get sick	36.64	48	27.78	20	47.46	28	0.020
Health professionals control your health	33.59	44	26.39	19	42.37	25	0.054
No matter what you do, you are likely to get sick	32.06	42	31.94	23	32.20	19	0.97
When you get sick, you are to blame	26.72	35	23.61	17	30.51	18	0.37
Regarding your health, you can only do what your doctor tells you to do	25.95	34	16.67	12	37.29	22	0.0074
Your good health is largely a matter of good fortune	22.90	30	22.22	16	23.73	14	0.84
Luck plays a big part in determining how soon you will recover from an illness	11.45	15	12.50	9	10.17	6	0.68

responses are provided only for illustrative purposes due to the overall (high) number of comparisons involved.

Discussion

We did not find many significant differences between those with severe PrUs and high medical co-morbidities vs. those with fewer co-morbidities. Instead, we observed a high degree of medical co-morbidity overall and were struck by the complex demands placed on these people to manage multiple chronic conditions in addition to their serious PrUs. Whereas we describe some opportunities for improvement, we also did not observe high rates of maladaptive health beliefs, wholly inadequate knowledge, or lack of motivation to improve skin-related health behaviors. These findings potentially point to the need for additional health systems research on how best to support knowledge and self-management of multiple chronic illness conditions simultaneously.

Most of the study ulcers were stage IV (73%), and almost 40% of the sample had two or more concurrent PrUs. Subjects reported a mean of 6.7 co-morbid conditions and the overall mean score for the Salzberg PrU risk assessment fell into the highest PrU risk

category. Subjects had diverse co-morbid conditions, including respiratory disease (66%), gastrointestinal (51.2%), and autonomic dysreflexia (47%), whereas others had conditions believed to increase PrU risk including renal disease or UTI (50%), diabetes (33%), and constant moisture (19%).

Our results for the PrU knowledge items are substantially higher (mean = 73.4% correct) than the average percent correct (54.5%) among people with SCI and PrUs in a previously published study.²³ However, when considering the level of knowledge needed in order to effectively manage or prevent PrUs over a lifetime, overall knowledge was low. Specific items with low scores that are especially relevant to prevention included the four stages of PrUs (57.9%), areas of the body are most likely to develop PrUs (62.3%), what they can do to prevent PrUs (66.1%), and steps to be taken if skin breakdown occurs (78.6%).

A substantial percentage of the sample reported daily, weekly, or monthly problems with bowel or bladder incontinence. This is even more problematic when considered together with other protective behaviors like bathing, with only half of the study subjects reported as occurring daily. This number could reflect a lack of

emphasis on cleanliness or, more likely, having to depend on others for bathing assistance.

Most subjects report not using street drugs or drinking to excess; however, about 10–12% report putting themselves at risk in this way. Large proportions of the sample reported that they did not follow commonly recommended skin care behavior guidelines and struggle with good nutrition. Guideline-recommended behaviors vary in difficulty of implementation and whether they are complicated by lack of access, and can be done independently or require assistance. Use of and barriers to adhering to skin protective behaviors should be an ongoing topic of discussion between patients and providers in order to identify changes in behavior or ability, ascertain an individual's readiness to change and provide access to resources that are available to assist them.

The results for the health belief questions suggest a further opportunity for continued risk reduction efforts. Most subjects believe that PrUs are serious and that they themselves are at risk for recurrence. However, substantial proportions of the sample report difficulties associated with good skin care practices, especially those that require internal motivation or do not provide immediate feedback.

Our data on the health locus of control scales were mostly unremarkable in terms of the overall internal, powerful other and chance orientations. There was a trend for subjects with higher co-morbidities to attribute their health more to chance factors. Perhaps the experience of having more medical problems creates a degree of fatalism about their susceptibility to illness. Of note, there is no commensurate decline in internal health locus of control among those with greater medical co-morbidities. This suggests that people with SCI can ascribe health problems to chance factors while simultaneously believing that they should take control of their health and that their actions make a difference. In terms of prior research, one study found a relationship between higher scores on the chance subscale and low-pressure ulcer knowledge in persons with SCI.^{25–27} Other studies have found no relationship between health locus of control and skin-related factors in SCI.^{28,29}

Although modifiable risk factors did not vary as a function of medical co-morbidity, data from the theory-based measures can be used to draw conclusions about the sample as a whole. First, PrU knowledge remains suboptimal suggesting a need for ongoing educational interventions. Next, the high number of chronic medical co-morbidities implies that people with PrUs may benefit from approaches that help them learn

general principles regarding chronic disease management rather than teaching PrU management in isolation. The information obtained on readiness to change skin care behaviors serves as a reminder that changing health care behaviors is a process, not a single event and hints at ways clinicians can tailor their interventions to the person's level of readiness. For example, with regard to daily skin checks, about 10% are not ready to change or unsure indicating that they may benefit from discussions about the importance or necessity of skin checks. In contrast, about 25% were either ready to change or trying to change, indicating that they need to be engaged at the level of understanding what they have already tried, what barriers they are facing to implementation, and how they can fit skin checks into their daily lives. Our data suggest that participants' general loci of control beliefs are typical. Health belief model results indicate that almost all participants think that pressure ulcers are serious and that performing skin care behaviors is an effective means of prevention. However, fewer believe that they are personally susceptible to experiencing recurrent pressure ulcers, especially among those with fewer co-morbid medical conditions. In addition, a minority report having difficulty following good skin care practices. Therefore, a potential direction for future research is on perceived susceptibility.

If one examines the study findings as a whole (ulcers are mostly severe, mostly recurrent, most have been present for more than a year and occur in the context of having multiple other co-morbid medical and psychological conditions with which to cope), interventions aimed at improving patient knowledge or adherence seem inadequate. Instead, it seems prudent to consider potential systems level changes to achieve better patient outcomes. One of the most successful models medical researchers have used to improve outcomes in patients with other complex, chronic medical conditions is the Chronic Care Model (CCM).³⁰ The CCM posits that outcomes for individuals with complex chronic care needs can be improved when health systems are reorganized to proactively support, inform, monitor, and activate patients to become better self-managers. Published literature in populations with chronic conditions suggests that many in our sample could benefit from proactive interdisciplinary approaches that attend to all the common medical co-morbidities and skin management simultaneously.³¹

Elements of the CCM that could be studied among people with SCI and PrUs are as follows. While an individual is hospitalized, electronic decision support tools and clinical reminders could be tested as a means of

ensuring that standard tests, clinical evaluations, and treatments are conducted in accordance with clinical practice guidelines for all of an individual's chronic conditions during their hospitalization. Also, while in hospital, it would be interesting to test the efficacy of standard PrU prevention training vs. training in more general chronic disease self-management skills (e.g. Chronic Disease Self Management Program developed by Lorig *et al.*)^{32,33} or training that involves how patients will be able to manage all their different chronic conditions simultaneously. Once the patient is discharged from the hospital, it would be interesting to study the efficacy of proactive follow-up, perhaps by telephone, to assist them to adapt and generalize new knowledge and skills to their home environment or to ensure that the patient carries out specific recommendations made by the team. The use of newer technologies to support in-home self-management should also be studied – for example, devices that administer disease management protocols via distance technology (e.g. Health Buddy®, Bosch Healthcare, Stuttgart, Germany) or automatic text messaging to promote adherence to self-care habits, or face-time or other video conferencing or photo sharing technologies to obtain real-time information on the status of skin healing.

It appears that despite the best efforts of all relevant stakeholders, our current system of care is not as effective in preventing the development or recurrence of severe PrUs in the SCI population. Prevalence rates of serious PrUs and recurrence are high despite marked improvements over the last few decades in equipment, treatments, etc. The degree to which clinical practice guidelines (CPGs) are being implemented by providers remains unclear.³⁴ Our data suggest that many of these factors are difficult to implement and sustain and rely on individuals to make changes and maintain them on their own. It may be that the current ethos of independence that drives rehabilitation care after SCI needs to focus more on incorporating “interdependence,” wherein individuals with chronic conditions are taught self-management skills and how to interact and reach out to providers when they need help. Even the idea of asking for help is problematic for many people, who may need more education and support to successfully self-advocate to prevent and/or report skin breakdown. It is also not clear that there is a general consensus about what aspects of self-care providers want patients to manage on their own vs. seek out help for from their providers. Availability of community-based programs to which outpatients can be referred for assistance with skin management vary as

well, so that even when providers are highly motivated to support self-management, the tools they have to work with may not be readily available at all sites.

Limitations

One potential limitation of our study is that we did not conduct formal cognitive screening (e.g. neuropsychological or dementia). Instead, we relied on medical records review and/or clinical judgment of the subject's primary care provider to exclude a potential subject due to cognitive impairment. If, at the time we tried to obtain the consent to participate in the study there was any doubt whatsoever about the subject's cognition, they were excluded.

Conclusion

Effective approaches to skin management for community-dwelling people with SCI may need to be supplemented by treatment models that recognize the complex chronic disease aspects this population faces. Comprehensive models of chronic disease management that include education, self-management skills, decision support for the health care system and proactive behavior change support to reduce PrU incidence and recurrence in people with SCI should be investigated.

References

- 1 Krouskop TA, Noble PC, Garber SL, Spencer WA. The effectiveness of preventive management in reducing the occurrence of pressure sores. *J Rehabil Res Dev* 1983;20(1):74–83.
- 2 Chen Y, DeVivo MJ, Jackson AB. Pressure ulcer prevalence in people with spinal cord injury: age-period-duration effects. *Arch Phys Med Rehabil* 2005;86(6):1208–13.
- 3 Schryvers OI, Stranc MF, Nance PW. Surgical treatment of pressure ulcers: 20-year experience. *Arch Phys Med Rehabil* 2000;81(12):1556–62.
- 4 Young JS, Burns PE. Pressure sores and the spinal cord injured: part II. *SCI Digest* 1981;3:11–26, 48.
- 5 Carlson CE, King RB, Kirk PM, Temple R, Heinemann A. Incidence and correlates of pressure ulcer development after spinal cord injury. *J Rehabil Nurs Res* 1992;(1):34–40.
- 6 Fuhrer MJ, Garber SL, Rintala DH, Clearman R, Hart K. Pressure ulcers in community-resident persons with spinal cord injury: prevalence and risk factors. *Arch Phys Med Rehabil* 1993;74(11):1172–7.
- 7 Smith BM, Guihan ML, LaVela SL, Garber SL. Factors predicting pressure ulcers in veterans with spinal cord injuries. *Am J Phys Med Rehabil* 2008;87(9):750–7.
- 8 Cardenas DD, Hoffman JM, Kirshblum S, McKinley W. Etiology and incidence of rehospitalization after traumatic spinal cord injury: a multicenter analysis. *Arch Phys Med Rehabil* 2004; 85(11):1757–63.
- 9 Regan MA, Teasell RW, Wolfe DL, Keast D, Mortenson WB, Aubut JA. Spinal Cord Injury Rehabilitation Evidence Research Team. A systematic review of therapeutic interventions for pressure ulcers after spinal cord injury. *Arch Phys Med Rehabil* 2009;Feb; 90(2):213–31.
- 10 Gélis A, Stéfán A, Colin D, Albert T, Gault D, Goossens D, *et al.* Therapeutic education in persons with spinal cord injury: a review of the literature. *Ann Phys Rehabil Med* 2011;54(3):189–210.
- 11 Gélis A, Dupeyron A, Legros P, Benaim C, Pelissier J, Fattal C. Pressure ulcer risk factors in persons with SCI: Part I: Acute and rehabilitation stages. *Spinal Cord* 2009;47(2):99–107.

- 12 Gélis A, Dupeyron A, Legros P, Benaïm C, Pelissier J, Fattal C. Pressure ulcer risk factors in persons with spinal cord injury part 2: the chronic stage. *Spinal Cord* 2009;47(9):651–61.
- 13 Burns SP, Hammond M. *Yes You Can! A guide to self-care for persons with spinal cord injury*. 4th ed. Washington, DC: Paralyzed Veterans of America; 2009.
- 14 DiClemente CC, Prochaska JO. Self-change and therapy change of smoking behavior: a comparison of processes of change in cessation and maintenance. *Addict Behav* 1982;7(2):133–42.
- 15 Consortium for Spinal Cord Medicine. Pressure ulcer prevention and treatment following spinal cord injury: a Clinical Practice Guideline for Health-Care Professionals. *J Spinal Cord Med* 2001;Spring;24(Suppl 1):S40–101.
- 16 Salzberg CA, Byrne DW, Cayten CG, van Niewerburgh P, Murphy JG, Viehbeck M. A new pressure ulcer risk assessment scale for individuals with spinal cord injury. *Am J Phys Med Rehabil* 1996;75(2):96–104.
- 17 Dai YT, Catanzaro M. (1987) Health beliefs and compliance with a skin care regimen. *Rehabil Nurs* 1987;12:13–6.
- 18 Guihan M, Garber SL, Bombardier CH, Durazo-Arizu R, Goldstein B, Holmes SA. Lessons learned while conducting research on prevention of pressure ulcers in veterans with spinal cord injury. *Arch Phys Med Rehabil* 2007;88(7):858–61.
- 19 Charlson ME, Pompei P, Ales KL, MacKenzie CR. A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. *J Chronic Dis* 1987;40:373–83.
- 20 Deyo RA, Cherkin DC, Ciol MA. Adapting a clinical comorbidity index for use with ICD-9-CM administrative databases. *J Clin Epidemiology* 1992;45(6):613–9.
- 21 Garber SL, Rintala DH, Holmes SA, Rodriguez GP, Friedman J. A structured educational model to improve pressure ulcer prevention knowledge in veterans with spinal cord dysfunction. *J Rehabil Res Dev* 2002;39(6):575–88.
- 22 LaBrie JW, Quinlan T, Schiffman JE, Earleywine ME. Performance of alcohol and safer sex change rulers compared with readiness to change questionnaires. *Psychol Addict Behav* 2005;19(1):112–5.
- 23 Rosenstock IM. Historical origins of the health belief model. *Health Educ Monographs* 1983;2:328–35.
- 24 Wallston BS, Wallston KA, Kaplan GD, Maides SA. The development and validation of the health related locus of control (HLC) scale. *Consult Clin Psychol* 1976;44(4):580–5.
- 25 Collins EG, Langbein WE, Smith B, Hendricks R, Hammond M, Weaver F. Patients' perspective on the comprehensive preventive health valuation in veterans with spinal cord injury. *Spinal Cord* 2005;43:366–74.
- 26 Hart KA, Rintala DH, Fuhrer MJ. Educational interests of individuals with spinal cord injury living in the community: medical, sexuality, and wellness topics. *Rehabil Nurs* 1996;21(2):82–90.
- 27 Gélis A, Stéfán A, Colin D, Albert T, Gault D, Goossens D, *et al*. Therapeutic education in persons with spinal cord injury: a review of the literature. *Ann Phys Rehabil Med* 2011;54(3):189–210.
- 28 Garber SL, Rintala DH, Holmes SA, Rodriguez GP, Friedman J. A structured educational model to improve pressure ulcer prevention knowledge in veterans with spinal cord dysfunction. *J Rehabil Res Dev* 2002;39(5):575–88.
- 29 Krause J, Stanwyck CA, Maides J. Locus of control and life adjustment. *Rehabil Counsel Bull* 1998;41:162–72.
- 30 Wagner EH. Chronic disease management: what will it take to improve care for chronic illness? *Eff Clin Pract* 1998;Aug–Sept; 1(1):2–4.
- 31 Coleman K, Austin BT, Brach C, Wagner EH. Evidence on the Chronic Care Model in the new millennium. *Health Aff (Millwood)* 2009;28(1):75–85.
- 32 Lorig KR, Holman H. (2003) Self-management education: history, definition, outcomes, and mechanisms. *Ann Behav Med* 2003; 26(1):1–7.
- 33 Lorig KR, Laurent DD, Deyo RA, Marnell ME, Minor MA, Ritter PL. Can a back pain e-mail discussion group improve health status and lower health care costs? A randomized study. *Arch Intern Med* 2002;Apr 8;162(7):792–6.
- 34 Thomason SS, Evitt CP, Harrow JJ, Love L, Moore DH, Mullins MA, *et al*. Providers' perceptions of spinal cord injury pressure ulcer guidelines. *J Spinal Cord Med* 2007;30(2):117–26.