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A database of self-reported secondary medical problems among VA spinal cord injury patients: Its role in clinical care and management

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Abstract—An interactive data management (IDM) system for the Spinal Cord Injury (SCI) Service was developed to collect self-reported patient data related to secondary medical complications and to provide feedback to the SCI rehabilitation team. The long-term objective is to improve clinical care through a process of staff review of current rehabilitation programs in the areas of prevalence, prevention, and management. Based on data from the first 99 SCI patients visiting the clinic and hospital after the installation of the IDM system, SCI patients reported high rates of current problems with spasticity (53 percent), pain (44 percent), and pressure ulcers (38 percent). Respiratory (12 percent) and bowel (14 percent) problems were less common current problems. The SCI staff questioned the reportedly high spasticity rates. They thought that the patients' answers might have indicated simply the occurrence of spasticity, rather than the more important issue of severe spasticity that interferes with daily activities. The staff suggested several additional spasticity questions to add to the study. In other areas, only a small percentage of patients wanted to talk with a therapist about prevention of pressure ulcers. Patients who had urinary problems consistently reported five urinary signs (e.g., cloudy urine). The clinical staff found these data informative and stated that they should continue to be collected.

Key words: *pain, pressure ulcers, spasticity, spinal cord injury, urinary tract infections.*

INTRODUCTION

The spinal cord injury (SCI) rehabilitation team needs feedback on the effectiveness of their therapeutic interventions and programs (1–6). In the Veterans Administration (VA), SCI care involves a large proportion of aging and long-term patients where rehabilitation of secondary medical complications is the primary endeavor. For these individuals, pressure ulcers are the primary reasons for hospital admissions, followed by urinary tract infections (4,7,8). Other secondary medical complications include pain, spasticity, bowel problems, bladder problems, respiratory complications, obesity, and diabetes (2–5).

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The Agency for Health Care Policy and Research (AHCPR) has developed clinical practice guidelines for the treatment of pressure ulcers (9). Evidence-based rehabilitation practices have also been developed for the management and prevention of other secondary complications (see the National Guideline Clearing House (www.guideline.gov) and the American Paraplegia Society) (10). However, SCI VA services do not collect their own patient data to judge the effectiveness of guidelines. Furthermore, practices for this long-term and aging SCI VA population may need to be modified to meet special needs. Such modifications need a patient database for assessment and evaluation of programs.

Large databases have been developed to evaluate clinical and rehabilitation practices (1–6), and several are directed at SCI rehabilitation. The Model Spinal Cord Injury Systems comprise a national registry that tracks the prevalence of SCI, SCI secondary complications, and functional outcome (2,3). The National VA Spinal Cord Dysfunction (SCD) Registry is a local and national registry for VA SCI rehabilitation parameters (11). The VA Veterans Health Information Systems and Technology Architecture (VISTA) can provide health summaries for each VA patient. However, these systems were not designed to track and report outcomes of the many factors in a rehabilitation program that are associated with secondary medical complications. A small local database is a promising tool to investigate new or local problems. Such a system can be easily modified to respond to medical service needs.

A new clinical database in the Hines VA SCI Service was designed for tracking and providing timely feedback to staff about the many issues associated with long-term secondary medical complications (4–6). This database uses an interactive data management (IDM) system that was developed by the Hines VA Hospital Cooperative Studies Program Coordinating Center for interactive data entry in multicenter clinical trials (12). This paper presents summaries, prepared for review by SCI staff, of the problems that their patients reported most frequently and of related activities conducted at home, such as prevention and rehabilitation activities.

METHODS

This study was conducted at Hines VA Hospital SCI Service. This is a large VA facility in the Chicago metropolitan area. Veterans using this facility come from Illinois, Eastern Wisconsin, Iowa, Western Indiana, and Michigan. This Service functions as an interdisciplinary treatment team that provides a wide range of treatment options in multiple settings, including inpatient hospital wards, an outpatient clinic, a home-care program, and a residential facility. Most patients are over the age of 50 and have had injuries for more than 10 y (5,6).

A new database was installed in the Hines VA SCI Service (4–6). This IDM uses screen entries that are organized by study forms and includes patient reports, medical records, and physician reports (12). To date, only patient report forms have been used. Patients who were being treated in the SCI outpatient clinic or who were hospitalized in one of the two SCI wards were invited to participate in a structured interview that used the staff-developed questions (4–6). Answers were entered directly into the IDM system by the interviewer. None of the patients declined to enter the study.

All questions were asked during initial entry into the study and only initial enrollment data are presented here. The questionnaire focused on patient self-reported medical problems, prevention activities practiced at home, and satisfaction with medical service. This report examines the most frequently reported problems: spasticity, pain, pressure ulcers, bladder problems, bowel problems, and respiratory problems. Associations between factors and the report of a secondary medical problem were assessed for statistical significance by Chi-square tests ($p < 0.05$).

RESULTS

Table 1 presents the current prevalence of nine secondary complications for the 99 patients enrolled. Patients responded to a series of questions asking “Are you having a current problem with (1) pressure ulcers, (2) spasticity, (3) pain, etc.,” with the responses of “yes/no.” The most common secondary complication reported was spasticity (53 percent)

Presented in **Table 2** are the related symptoms for patients with current spasticity (n = 52) or pain (n = 42). Spasticity manifests itself primarily in the lower legs. Medications and limb movements are used for spasticity management in most patients, and nearly all of the patients were either satisfied or very satisfied with their management of spasticity. Pain manifests itself primarily below the level of the injury and in multiple locations.

Table 1.
Current prevalence of secondary medical problems perceived by SCI patients (n = 99).

Current Problem	Frequency (%)
Spasticity	53
Pain	44
Pressure ulcers	38
Bladder problem	22
Nutrition/Obesity/Exercise	17
Bowel problem	14
Respiration problem	12
Social problems/Concerns with relationships	7
Self-care problems	2

Nearly half the patients reported severe pain and pain that interfered with daily activity. However, a large majority were somewhat or very satisfied with their pain management program. A majority of patients used pain medication, range of motion exercises, bed rest, and daily activity to manage pain.

Related symptoms for patients with current pressure ulcers (n = 38), bladder (n = 22), bowel (n = 14), or respiratory problems (n = 12) are shown in **Table 3**. Pressure ulcers occurred primarily in the sacral, ischial, and trochanter areas. A large majority of patients were satisfied with their ulcer prevention program, and few wanted to see a therapist to help prevent pressure ulcers. Bladder problems commonly involved urinary tract infection (UTI) and incontinence. Patients with bowel problems commonly reported problems of hard stool, the bowel program taking too long, and impaction. Shortness of breath is the most common respiratory problem symptom. Approximately half those with respiratory problems were using respiratory inhalants prescribed by their doctor.

Table 4 examines the association between patient characteristics or preventive practices and the presence of pressure ulcers. The rate of self-report of large abdominal girth among patients with pressure ulcers is more than four times the rate for those without ulcers. Activities to prevent pressure ulcers were grouped into wheelchair or bed practices. Programs to relieve pressure ulcers in the wheelchair included periodic raising of the bottom or leaning from side-to-side. Raising the body and leaning were done by a majority of the patients. However, these activities were as frequent for patients with current pressure ulcers as in patients with no current ulcers. Patient hygiene practices were also common in those with and without current ulcer problems. Associations between patient characteristics or preventive practices and current bladder problems are examined in **Table 5**. The rates of the five specific urological problems (cloudy urine, etc.)

Table 2.
Specific complications in patients reporting current spasticity or pain.

Current Secondary Problem	Specific Complication	Frequency (%)
Spasticity (n = 52)	In lower legs	81
	Spastic contractions in limbs	71
	In arms	25
	Problem straightening legs or arms	23
	Management program	
	Use antispasticity medications	77
	Use limb flexion for management	75
	Satisfied with management program	
	Somewhat	76
	Very	14
Pain (n = 42)	Location	
	Occurrence below level of injury	68
	Back pain	59
	Shoulder pain	52
	Elbow pain	36
	Severity	
	Pain interferes with normal activities	59
	Severe pain	48
	Comorbidity	
	Broken bone	16
	Joint fixation	9
	Pain Management per patient	
	Medication for pain	70
	Range of motion exercises	68
	Resting or lying in bed	65
	Daily activity or exercise	61
	Adjusting position in chair	43
	Decreased use of arms	39
	Tylenol	25
	Surgery for pain	5
	Satisfied with pain control program	54

Table 3.
Specific complications in patients reporting current pressure ulcers, bladder problems, or respiratory problems.

Current Secondary Problem	Specific Complication	Frequency (%)
Pressure ulcers (n = 38)	Sacral, ischial, or trochanter	71
	Want to see a therapist to help prevent ulcers	21
	Satisfied with ulcer prevention program	82
Bladder problem (n = 22)	Urinary tract infection	59
	Need help with bladder emptying	59
	Urinary incontinence	55
	Difficulty emptying bladder—sitting	27
	Difficulty emptying bladder—lying down	23
	Headaches from bladder contraction	18
Bowel problem (n = 14)	Stool too hard	57
	Bowel program takes too long	50
	Impaction	43
	Stool too soft and watery	21
	Diarrhea	14
Respiratory problem (n = 12)	Shortness of breath	67
	Respiratory inhalants by doctor	42
	Respiratory infections	25
	Nasal PAP	8
	Satisfied with respiratory program	83

Table 4.
Association between patient characteristics or preventive practices and current pressure ulcer problems.

Patient Characteristics and Preventive Practices		Patients w/Current Ulcers (n = 38) (%)	Patients w/o Current Ulcers (n = 58) (%)
Risk factors	Abdominal girth much greater than normal	29	7*
Wheelchair cushion	Less than 3 years old	94	78*
	Use Ro Ho cushion	55	53
Preventive wheelchair practices	Raising bottom 20 min. or less	58	46
	Raising bottom 1 h or less	85	85
	Leaning side to side	89	83
Preventive bed practices	Rotation twice per night	87	86
	Use supports or pillows	71	69
	Rotation in bed every 2 h during day	19	41*
Prevention with personal hygiene	Keep skin clean and dry	100	100
	Clean urine immediately from skin	100	100
	Wash with soap and water daily	97	100
	Avoid skin irritation, such as harsh soaps	97	100
	Check risk areas for redness	97	88
	Increased pressure relief from red areas	89	85
	Keep finger and toe nails short	76	93
	Reduce calluses with moist creams	68	70

*Statistically significant association: Chi-square; $p < 0.05$.

were consistently much higher among patients with current bladder problems, and the differences are statistically significant. Patients with and without current bladder problems had similar rates of general urological preventive activities. No single catheterization method was associated with the presence or absence of bladder

Table 5.
Association between patient characteristics or preventive practices and reported current bladder problems.

Patient Characteristics and Preventive Practices		Patients with Current Bladder Problems (n = 22) (%)	Patients without Current Bladder Problems (n = 77) (%)
Specific urological problems	Cloudy urine	50	19*
	Foul smelling urine	45	8*
	Blood in urine	14	1*
	Urinary tract infection	59	6*
	Urinary incontinence	55	16*
General urological problem prevention activities	Betadine with catheterization	29	32
	Use lots of lubricants on catheter	61	46
	Drink 6–8 glasses of water daily	77	90
	Limit fluid intake in evening	19	38
Method of urological management	Foley catheterization	24	20
	Intermittent catheter	32	22
	External drainage (condom) catheter	67	65
	Volitional voiding and urinals	29	16

*Statistically significant association: Chi-square; $p < 0.05$.

complaints. Patients often used more than one method, as the four methods shown add to more than 100 percent. Additional comparisons (data not shown) showed that 12 (50 percent) of the 24 patients who used Foley catheters changed them more than once each month, 19 (83 percent) of the 23 patients on intermittent catheterization had catheterizations spaced at least 4 h apart and 43 percent used sterile catheters, and 40 (65 percent) of the 62 patients who used external (condom) catheters changed their condoms daily.

Patient characteristics and associations with current bowel problems are shown in **Table 6**. Individuals with a bowel problem used suppositories more frequently. All other elements of the bowel program were of comparable frequency in patients with or without bowel problems. Less than 40 percent of the patients reported using laxatives, stool softeners, or enemas. In addition, these items were as likely to be used by those with bowel problems as without problems.

Table 7 depicts associations between patient characteristics and preventive practices and current respiratory problems. The frequency of large abdominal girth among patients with current respiratory problems is five times greater than the frequency for patients without current respiratory problems. The majority of patients conducted activities to prevent respiratory problems. Patients without current respiratory problems were more likely to drink two or three quarts of water daily than patients reporting a respiratory problem, with a statistically significant difference. Exercises, such as deep breathing, quad cough, incentive spirometry, and inspiratory resistance were done infrequently.

DISCUSSION

The summaries presented in this report demonstrate the role of a local system in collecting patient data for clinical assessment. This preliminary survey of secondary complications, based on patient self-assessment during an interview, indicated that spasticity, pain, and pressure ulcers were common problems of SCI patients. The survey also showed that follow-up questions can clarify the many issues associated with secondary complications such as the severity of problems, associated risk factors, the need for further interventions, and the patient's desire for further treatment. Verification of patient-reported symptoms is needed, including clinical tests and signs, as part of standard clinical practice. However, the SCI Service team felt that reported patient perceptions provided important information about their rehabilitation programs and that patient-reported data should continue to be collected.

Table 6.
Association between patient characteristics or preventive practices and reported bowel problems.

Patient Characteristics and Preventive Program		Patients with Current Bowel Problems (n = 14) (%)	Patients without Current Bowel Problems (n = 85) (%)
Bowel program	Use suppositories	71	41*
	Use digital procedures	64	64
	Need help with evacuation	38	37
	Use laxative	36	26
	Use stool softener	36	19
	Use enema	25	29
	Use bulk formers	7	1
Frequency of bowel program	Daily or volitional	54	36
	2d or 3d day	31	58
	4th day or variable	15	6

*Statistically significant association: Chi-square; $p < 0.05$.

Table 7.
Association between patient characteristics or preventive practices and current respiratory problems.

Patients Characteristic and Preventive Measures		Patients with Current Respiratory Problems (n = 12) (%)	Patients without Current Respiratory Problems (n = 87) (%)
Risk factors	Abdominal girth much greater than normal	50	10*
Preventive measures	Good general health habits	83	95
	Sit in wheelchair daily	67	87
	Drink 2 or 3 quarts of fluid daily	67	90*
	Maintain humid environment	58	48
	Deep breathing exercise 3 or 4 times daily	25	15
	Postural drainage	17	0*
	Inspiratory resistance muscle training	8	6
	Incentive spirometry for vital capacity	0	5
	Quad cough	0	1

*Statistically significant association: Chi-square; $p < 0.05$.

Although spasticity is a well-known problem for individuals with SCI (13–17), the clinical staff was surprised by the high rate of spasticity problems reported to the independent interviewer in this study. The staff was particularly concerned that patients may have reported simply the presence of spasticity rather than a problem with spasticity. The specific information that was desired pertained to spasticity that interferes with daily activities.

Subsequently, the staff suggested that four important follow-up questions be added to the survey to assess further the patients' perceptions of the severity of this problem, namely:

1. Does the spasticity interfere with daily activity?
2. Does the spasticity interfere with transfers?
3. Does current spasticity management have problems such as medication side effects?
4. Do patients want more information on spasticity management programs?

The clinical staff pointed out that new interventions are being used for spasticity that should increase patient satisfaction in this important area. Tizanidine, an alpha-2 agonist and antispasticity medication, has an improved side-effect profile (18). Botulinum toxin, a muscle paralyzing agent, is injected into spastic muscles with little or

no side effects (19). We recently reported that improvement in spasticity with regular standing in mobile standing devices (20,21) and that dorsal flexion of the foot while standing may further inhibit spasticity (22). In this report, a significant number of patients had standing equipment and were using it. However, the beneficial effects of new medications or regular home standing will need to be clarified with future observation

The clinical staff discusses pain issues with every patient at every clinic visit, and all pain problems are treated. Common pain management methods include medication and decreased use of arms. The clinical staff suggested additional follow-up questions to assess further patient needs in this important area:

1. Do you want more information on pain management programs?
2. Do you want additional pain management treatments?
3. Are you having a problem with medication side effects?

The clinical staff also pointed out that new interventions are being used for pain management and felt that pain outcome data should be collected to assess these new options.

Pressure ulcers are a common secondary medical problem for individuals with SCI (16,23,24). For this survey, the clinical staff was impressed and pleased by the high percentage of patients reporting active prevention activities, such as pressure relief every hour or less while sitting, to cope with sacral and ischial pressure ulcers. Nearly all patients reported conducting important prevention activities such as observing their skin and conducting increased pressure relief for red areas. However, the staff thought more information on prevention activities of patients was needed and wished to add three questions to the database:

1. How long were they sitting in their chairs?
2. How many times per day did they go for 1 h or longer without doing pressure relief while in their wheelchair?
3. How consistently were pressure relief activities conducted?

The staff was concerned that further changes in prevention activities would not be easily introduced because, based on the current responses, most patients were satisfied with their current pressure relief program and very few patients wanted to see a therapist to help prevent ulcers.

In this report, large abdominal girth was associated with pressure ulcers and respiratory problems. Patient-reported abdominal girth has limitations based on perceptions of what is normal. This measure needs to be verified with direct measures of abdominal girth and percent body fat and will be added in the future. However, obesity is a well-known risk factor for many secondary complications of SCI, including cardiovascular problems, diabetes, and pressure ulcers. In addition, obesity has been associated with the sedentary lifestyles that these individuals often exhibit (14,16,24–26). Thus, lifestyle activities related to nutrition and physical exercise are accepted as an important part of SCI rehabilitation (13,25,26). Exercise programs for the home environment can have low associated costs. For example, use of 5- to 15-lb dumbbells and videotapes for wheelchair exercises can be fun for the individual and introduced easily into the home environment.

Urine characteristics such as cloudy, foul smelling, or blood in the urine were highly associated markers for urinary problems and have been reported elsewhere (15,27–29). Closer tracking of these markers in the clinic as well as with patient-reported opinions could result in earlier assessment and management. In this survey, those with bowel problems were concerned with constipation, impaction, and extended time to conduct bowel programs. Surprisingly, few patients with current bowel problems reported using laxatives or stool softeners. The clinical staff thought that a higher percentage of patients were actually prescribed these medications and that patients should be urged to use laxatives and stool softeners more frequently for constipation-related problems, along with other therapies. In our recent survey of SCI patients using standing devices, patients with at least 0.5 h of daily standing reported improved bowel function (20,21). More questions related to the benefits of medication and standing for bowel function are proposed for continuations of this survey.

CONCLUSION

The Hines SCI database has been designed to track current and longitudinal clinical data for patients with SCI. This report provided SCI staff with a summary of the problems and activities of their current patients and of

how they are doing at home, related to their prevention and rehabilitation programs. As patients return for clinic visits, more longitudinal data can be collected that can serve as outcome data for the therapeutic programs that the VA SCI Service uses. In addition, as funding becomes available, clinical tests and signs will be added to the database to provide authentication of patient-reported symptoms. Outcome measures will keep the SCI staff informed about the most pressing problems and which rehabilitation programs are efficacious. The current small sample size has limitations that will be addressed by the enrollment of additional patients. However, the use of a flexible local database allows the clinic to add new questions to the database and to discard older questions that are no longer relevant. This is the kind of information system that an active rehabilitation program needs for assessment and revision of clinical practice.

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