
Secondary Conditions Experienced by Adults with Injury-Related Disabilities in Montana

Tom Seekins and Craig Ravesloot

Secondary conditions have recently emerged as a major issue affecting the health and independence of people with disabilities, but little is known about their prevalence or severity. The rates and severity of secondary conditions experienced by adults living in Montana (the second-most rural state) with disabilities related to injuries were assessed and were compared to rates of secondary conditions observed through state-wide surveillance of adults with disabilities related to other physical impairments. Survey techniques were used to collect self-reported experience with secondary conditions. Adult consumers of three centers for independent living, residents of three reservations, and a random selection of 1,000 from the state's handicapped parking registry were surveyed. Participants rated the severity of their experience with 40 secondary conditions. Data were analyzed using simple statistical procedures. Respondents reported experiencing an average of 15 secondary conditions annually. These data show a striking similarity in problems experienced across groups of people with different impairments, including problems of mobility, pain, physical conditioning, fatigue, access, sleep disturbances, contracture, depression, spasticity, and eating and weight regulation. The health and independence of adults with disabilities related to physical impairments do not appear to be as good as might be expected, even after years of community living experience. Eight of the top 12 problems might be addressed through wellness or lifestyle management programs. Key words: *disability, health, rural, secondary conditions*

RECENTLY, DISABILITY has come to be recognized as one of the nation's largest health issues.¹ Disability affects upwards of 51 million individuals in the United States.² This group represents 17% of the population, but it accounts for 47% of medical expenditures and as much as \$300 billion annually.³ Appropriately, the goal of promoting the health of people with disabilities to prevent further disability has emerged as a major item on the public health agenda.^{4,5}

The emergence of this goal has coincided with a broader acceptance of a biobehavioral model of disability.^{6,7} This model, consistent with developmental and ecological models of disability, portrays disability as an outcome of interactions between biological, environmental (physical and social), lifestyle, and behavioral risk factors. As such, the model offers a wide range of targets for interventions intended to improve health and

participation in society. It recognizes the possibility of reducing the effects of disability, once acquired, by preventing and managing secondary conditions.

Secondary conditions are additional complications experienced by a person with a disability that are associated with, but are acquired after, the primary impairment.⁸ These include impairments or functional limitations that contribute to additional disability. For example, impairment, such as a

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loss of range of motion experienced by an individual with a spinal cord injury (SCI) due to chronic pain and contracture, may involve the further loss of physical ability to perform desired activity. Likewise, functional limitations, such as the inability to use one's arms to pull effectively, may lead to further disability if there are no alternatives for achieving desired or expected goals that require reaching or pulling (e.g., opening a door) in a given environment. The personal and social cost of these secondary conditions is extraordinarily high. For example, treatment of pressure sores can run as high as \$91,000.^{9,10} Yet, many secondary conditions are preventable.

A major step in developing programs to prevent and manage secondary conditions in a population involves surveillance.¹¹ Surveillance allows public health planners and others to identify and monitor health conditions and risk factors within the population in order to target and evaluate interventions. Surveillance activities are often conducted in a way that allows multiple analyses of specific population subgroups. Such analyses help to target programs specific to the subgroups.

Traumatic injuries are one of the major factors contributing to the prevalence of disability.¹² For example, Pope and Tarlov¹ report that the rate of SCIs is approximately 5 per 100,000 annually and the rate of traumatic brain injuries (TBIs) is approximately 200 per 100,000 annually. Historically, the survival rate of individuals who experienced severe injuries was relatively low. Improvements in emergency response, trauma care, and medical treatment have led to an increase in overall survival rates of those with even the most severe spinal cord and brain injuries. According to the Pope and Tarlov

model, individuals who survive a severe injury are at risk of progressing from the pathology and associated impairments to functional limitations and then to disability. As such, people with injury-related disabilities constitute an important and growing population of people at risk for secondary conditions, but little is known about what secondary conditions they experience or which conditions produce the most limitation for the most people.

This article summarizes the data on secondary conditions experienced by a wide range of adults with physical disabilities living in Montana and compares those secondary conditions to secondary conditions experienced by individuals with SCIs, other orthopedic injuries, and TBIs. Results of several exploratory analyses of associations between selected risk factors and secondary conditions are also presented. These data were collected as part of a larger study examining secondary conditions among adults with mobility impairments.

Method

Participants

The prevalence of many specific impairments is relatively low; therefore, a very large sample of the population is required to collect data specific to a given impairment. Such requirements are particularly hard to meet in rural states with small populations, such as Montana. Alternately, large numbers of individuals experiencing a particular condition may be identified and contacted through organizations designed to serve people with those conditions. Even though this method raises concerns about the generality of results, we chose this approach for

efficiency. Respondents were selected from the mailing lists of three independent living centers (ILCs),* the Indian Health Service on three reservations, and Montana Department of Motor Vehicles' list of handicap parking permit holders. Surveys were distributed to 456 consumers of the three ILCs who had mobility impairments. Twenty-seven surveys were collected through direct interviews (by community health representatives) of the Indian Health Service on the three reservations. Finally, surveys were mailed to 1,000 holders of handicap parking permits who were randomly selected from the list kept by the state's Department of Motor Vehicles.

Preliminary analyses of the separate samples drawn from the ILCs, reservations, and handicap parking permit holders showed substantial similarity and indicated that these samples could be combined for an overall portrait of secondary conditions in Montana.^{13,14} Next, separate analyses were conducted to summarize all data for subgroups of individuals with disabilities related to various impairments. In this case, data for individuals that indicated they had injury-related disabilities were compared with each other and with the total sample.

Respondents who indicated that their primary disability was associated with SCI, other orthopedic injuries, or TBI were selected from the database. Only those who reported one of these conditions and no other

A primary purpose of conducting surveillance activities is to identify prevalent, severe, and costly problems that might be targeted for health promotion or preventive interventions.

injury-related disability were selected for this analysis. This procedure excluded, for example, individuals who reported having both an SCI and a TBI that may have been sustained in the same auto collision.

Procedures

We gathered information on secondary conditions in Montana using a questionnaire we developed, which queried consumers about secondary conditions and various demographic variables.^{15,16} Respondents were asked to rate the severity of 40 secondary conditions on a scale of 0 to 3, where 0 meant the condition had not been a problem during the past year, 1 meant a condition had been a mild or infrequent problem that limited activity 1 to 5 hours per week, 2 indicated a condition had been a moderate or occasional problem that limited activity 6 to 10 hours per week, and 3 meant that a condition had been a significant/chronic problem that limited activity 11 or more hours per week. Brief definitions were provided to help ensure that respondents understood each item's meaning.*

A primary purpose of conducting surveillance activities is to identify prevalent, se-

* Independent living centers are nonprofit community-based service and advocacy organizations that are run by people with disabilities. Generally, these centers are funded through Title VII, Part B, of the Rehabilitation Act and serve, primarily, adults with physical disabilities.

* Copies of the instrument, the Secondary Conditions Surveillance Instrument (SCSI), are available from the authors (raves@selway.umt.edu or 406-243-2447).

vere, and costly problems that might be targeted for health promotion or preventive interventions. Three measures of each secondary condition were calculated, including the percentage of consumers reporting limitation due to a condition (i.e., endorsing the item), the average severity rating reported by those endorsing the conditions, and a problem index score derived from the previous two measures. The number endorsing an item was calculated by totaling the number of respondents rating a secondary condition 1, 2, or 3. An average severity rating for each secondary condition was calculated by dividing the sum of severity ratings by the number endorsing the item. A problem index was calculated by multiplying the percentage endorsing by the average severity rating of each item. This measure combines both frequency of occurrence and severity. Thus, the problem index rank orders conditions by the most severe secondary conditions experienced by the most respondents.*

In addition to rating each secondary condition, respondents rated their overall health and independence on a 4-point anchored scale with choices including excellent, good, fair, and poor. To be consistent with ratings of the 40 secondary conditions, responses were coded so that 0 was excellent and 3 was poor health or independence.

Finally, the sum of secondary conditions was calculated by summing an individual's

ratings of all conditions. This arithmetic sum could total 120 for an individual, which was a maximum rating of 3 for each of the 40 conditions.

Data analysis

The primary focus of this study was the examination of secondary conditions experienced. Standard descriptive statistics were calculated for the whole sample and each of the injury subsamples. In addition, one-way analysis of variance (ANOVA) was used to compare the demographics and ratings of secondary conditions of the three subsamples.

We expected overall health and independence to be negatively associated with secondary conditions. In addition, exploratory hypotheses regarding associations between measures of secondary conditions and other potential risk factors were developed and tested. These included hypotheses of relationships between ratings of overall health, overall independence, and the sum of ratings of all secondary conditions. Specific hypotheses included the following: (1) Individuals who have a disability for a longer time are better adjusted to it and have better overall health and independence and fewer secondary conditions; (2) individuals with higher reported income have better overall health and independence and experience fewer secondary conditions because they are better able to afford care and treatment; (3) individuals who are older are more likely to have secondary conditions; and (4) individuals with more education are more likely to learn about and engage in preventive practice, thereby remaining healthier and more independent and experiencing fewer secondary conditions. We investigated these exploratory hypotheses by cal-

* Mathematically, the problem index is the same as the mean calculated by including those who reported not experiencing a condition. However, the explanation of calculating the problem index, rather than simply reporting a mean, has more didactic power than for the general public, consumers, service providers, and policy makers.

culating correlation coefficients between selected variables.

Results

Five hundred and ninety-four (594) consumers living in 44 counties of Montana completed the survey. Of these, 210 (46%) were consumers of the ILCs and 357 (35.7%) were holders of handicapped parking permits. Additionally, 27 American Indians who were interviewed by community health representatives completed surveys.

Table 1 lists the primary impairments reported by all 594 respondents. The total number of reported impairments adds to more than 594 because some people endorsed more than one. When individuals with disabilities associated with multiple impairments were excluded, that left 73 individuals with SCI, 55 with other orthopedic injuries, and 32 with TBI. Aggregating across injury

groups, 142 (88%) listed their race as white, 15 (9%) listed their race as Native American, 2 (1%) listed their race as Asian, and 1 (.6%) listed his or her race as Hispanic. The ages ranged from 9 to 87 years, with a mean of 51.4 years. Ninety-two (57%) respondents were men and 70 (43.2%) were women.

Table 2 presents a comparison of demographic characteristics of the total sample and of respondents with SCIs, other orthopedic injuries, and TBIs. For the total sample of 594, the median length of time since acquiring the primary disability was 18.5 years. The median income was \$15,284 with a range of \$0 to over \$100,000.

Table 3 presents the average number of secondary conditions reported by each group. In addition, their ratings of overall health and independence are presented.

Demographically, participants reporting other orthopedic injuries were older and had their injury longer than those reporting SCI

Table 1. Primary impairments reported by all respondents

Impairment	Respondents	Percentage
Arthritis	163	28
Spinal cord injury	81	14
Multiple sclerosis	74	13
Stroke	49	8
Traumatic brain injury	39	7
Polio	36	6
Amputee	28	5
Cerebral palsy	22	4
Muscular dystrophy	14	2
Parkinson’s disease	10	2
Spina bifida	4	1
Other	177	30
Total	697	100

Note: Total number of respondents = 594. Total number of impairments reported exceeds the total number of respondents due to multiple endorsements by some of the respondents.

Table 2. Demographic characteristics of sample

Characteristic	All respond (<i>N</i> = 594)	Spinal cord injury (<i>n</i> = 73)	Other orthopedic injury (<i>n</i> = 55)	Traumatic brain injury (<i>n</i> = 32)
Men	278	44	25	21
Women	311	29	30	11
Average age	57	44	61	49
Years disabled	18.5	11	19	13
Number in household		2.3	2.2	2.2
Annual income	\$15,284	\$16,470	\$15,510	\$12,960
Education	12	12.6	12.2	12.6
Unemployed	36%	42%	35%	56%
No insurance	11%	8%	16%	9%

or TBI. Further, those reporting other orthopedic injuries were more likely to classify themselves as retired and having Medicare coverage. Otherwise, no statistically significant difference emerged in the demographics of this sample, and they appeared similar in terms of gender, number in household, income, education, insurance coverage, overall health, and overall independence.

Table 4 presents measures of secondary conditions for all respondents, together with those for individuals reporting SCI, other orthopedic injuries, and TBI. The omnibus null hypothesis that there are no significant

differences across injury groups was tested for each secondary condition using one-way ANOVA. When the omnibus test was significant, post hoc comparisons were computed using the Newman-Keuls multiple comparisons test. Those secondary conditions that demonstrated statistically significant differences ($P < .05$) between injury groups are noted in Table 4.

Table 5 summarizes the results of the exploratory analyses of associations between measures of limitation due to secondary conditions and potential risk factors. As the analysis is exploratory, comparisons of cor-

Table 3. Overall health, independence, and secondary condition reported

Characteristic	All respond (<i>N</i> = 594)	Spinal cord injury (<i>n</i> = 73)	Other orthopedic injuries (<i>n</i> = 55)	Traumatic brain injury (<i>n</i> = 32)
Overall health	1.8	1.8	1.8	1.5
Overall independence	2.2	2.0	2.2	2.2
Average secondary conditions reported	14	16	14	14.6

Table 4. Comparison of secondary conditions reported by all respondents and those with injury-related disabilities

Condition	Overall (N = 594)		Spinal cord injury (n = 73)		Other orthopedic injuries (n = 55)		Traumatic brain injury (n = 32)	
	Mean severity	Problem index	Mean severity	Problem index	Mean severity	Problem index	Mean severity	Problem index
Problem with mobility	2.3	199	2.3	175	2.1	189	2.2	184
Joint and muscle pain	2.2	168	1.9	149	2.4	227 ^d	2.3	140
Physical conditioning problems	2.2	166	1.8	141	2.0	162	2.3	155
Fatigue	2.2	165	1.7	114	1.7	169 ^c	1.9	158
Chronic pain	2.3	159	2.2	161	2.6	219 ^d	2.1	110
Arthritis	2.4	144	2.2	92	2.5	217 ^d	2.2	90
Difficulties with access	2.1	143	1.9	176 ^a	2.0	100	2.4	116
Sleep disturbance	2.0	127	2.2	132	1.9	120	2.4	123
Contractures	2.2	125	1.9	107	2.4	176 ^d	2.1	120
Depression	2.0	108	2.1	115	1.7	90	2.0	116
Spasticity	2.1	107	2.1	141	1.9	110	2.0	111
Eating and/or weight regulation problems	1.9	105	1.7	97	1.8	116	1.8	77
Sexual dysfunction	2.2	103	2.0	110	2.6	126	2.3	100
Bladder dysfunction	2.0	98	1.8	121 ^b	1.9	85	1.6	42
Isolation	2.0	89	1.9	84	1.7	50	2.2	146 ^f
Written communication problems	2.3	89	2.3	68	1.7	40	2.4	122 ^g
Bowel dysfunction	1.9	89	1.5	103	1.9	69	1.8	74
Visual impairment	2.1	87	2.1	48	1.8	47	1.8	118 ^f
Cardiovascular	2.0	81	1.8	52	1.9	94	1.9	57
Medication side effects	2.1	80	1.9	68	2.2	108	2.0	60
Respiratory problems	2.0	80	1.9	81	1.9	72	1.4	37
Hearing impairment	1.9	70	2.0	61	1.5	64	1.9	94
Postural hypertension	1.7	63	1.8	72	1.7	58	1.9	97
Injuries related to loss of sensation	1.9	59	1.8	112 ^a	1.9	66	2.2	45
Urinary tract infection	1.8	58	1.7	103 ^a	1.5	27	1.8	54
Communication difficulties	2.0	56	1.9	39	2.0	17	2.3	130 ^f
Carpal-tunnel syndrome	2.0	54	1.8	50	1.9	62	1.7	32
Osteoporosis	2.1	53	2.0	63	2.4	66	2.0	40
Pressure sores	1.9	42	1.8	68 ^c	1.4	23	1.7	41
Autonomic dysreflexia	1.9	42	2.1	75 ^c	1.6	29	2.3	52
Anemia	1.9	40	1.7	25	1.6	30	1.8	30
Diabetes	2.2	36	2.0	8	1.9	27	1.7	17
Equipment failures	1.7	34	1.6	51	2.1	31	3.0	29
Heterotrophic bone ossification	1.9	33	1.6	33	2.3	64	1.7	34
Amputation	2.4	19	1.0	1	3.0	19	1.0	7
Alcohol/drug misuse	1.6	18	1.5	34	1.6	16	1.4	24
Equipment-related injuries	1.6	58	1.4	25	1.5	19	2.0	6
Care-related injuries to others	1.6	16	1.5	12	1.5	13	1.0	13
Care-related injuries	1.4	13	2.8	16	2.0	9	1.0	3
Equipment-related injuries to others	1.5	8	1.5	12	1.7	11	1.0	3

^aSCI greater than both. ^bSCI greater than TBI. ^cSCI greater than Orthopedic. ^dOrthopedic greater than both. ^eOrthopedic greater than SCI. ^fTBI greater than both. ^gTBI greater than Orthopedic.

Table 5. Exploratory analysis of association between selected risk factors and secondary conditions

Association	Spinal cord injury	Other orthopedic injuries	Traumatic brain injury
Time since disability and			
Overall health	.019	.076	-.502**
Overall independence	.107	.117	-.083
Sum of secondary conditions	.044	-.106	.226
Income and			
Overall health	.180	.137	-.030
Overall independence	-.036	-.052	-.111
Sum of secondary conditions	-.309*	-.061	-.047
Age and			
Overall health	-.288*	-.019	-.430*
Overall independence	-.236	.012	-.130
Sum of secondary conditions	.355**	-.098	.365*
Education and			
Overall health	.366**	.109	.233
Overall independence	.384**	.243	.177
Sum of secondary conditions	.334**	-.014	-.318
Overall			
Health and independence	.747**	.534**	.357
Health and sum of limitation due to secondary conditions	-.674**	-.423**	-.599**
Independence and sum of limitation due to secondary conditions	-.564**	-.404**	-.572**

*significant at $P = .10$, two-tailed. **significant at $P = .05$, two-tailed.

relations for associations showing statistical significance at the 0.10 as well as the 0.05 level or greater, for any group, are presented.

Discussion

This article presents results from state-wide surveillance of secondary conditions experienced by adults with disabilities related to physical impairments. The major feature of these data is the striking similarity of top-ranked items across the groups. Although the relative position and absolute ratings of these items vary for each injury-related group, the majority reported issues in

common, including mobility problems, joint and muscle pain, chronic pain, physical conditioning problems, fatigue, arthritis, difficulties with access, sleep disturbances, depression, and eating and weight problems. This is particularly striking because many of the more "medically oriented" problems emphasized in earlier literature were ranked lower in priority by this population.

A second important feature of these data is that all respondents reported experiencing an average of about 14 of the listed conditions annually. Those with injury-related disability reported an average of 15. This far ex-

ceeded initial expectations and suggests that many people with disabilities living in rural communities are faring far more poorly than might be expected.

These results should be interpreted with caution for several reasons. First, all respondents came from one rural state, and these results may not generalize to other areas of the country. Second, these data were collected from consumers of defined service programs and not from individuals selected randomly from the general population. As such, they may not be representative of all adults with injury-related disability. Still, the consistency of the data—especially the highly ranked common items—is suggestive of programs that may be potentially useful to a wide range of individuals.

In general, the results of the explanatory analysis of selected risk factors did not reveal strong patterns of correlation. However, significant relationships between overall health, overall independence, and the sum of secondary conditions were encouraging, lending support to the construct validity of the measures. In addition, this exploratory analysis suggests that for those with SCIs, education may have an ameliorating effect. On the other hand, the sum of limitation due to secondary conditions for that group appears to increase with age.

Although the similarity of problems reported is the major feature of these data, potentially important ranking differences can be seen across the various injury subgroups. Individuals with SCIs, for example, reported significantly higher levels of problems than either of the other two subgroups with access, injuries due to loss of sensation, and urinary tract infections; significantly greater problems than those with TBI with

bladder dysfunction; and significantly greater problems than those with other orthopedic injuries with pressure sores and dysreflexia.

Participants with other orthopedic injuries reported greater problems than either of the other two subgroups with joint and muscle pain, chronic pain, arthritis, and contractures and significantly greater problems with fatigue than those with SCI. All of these differences are consistent with anecdotal reports and clinical observations.

Similarly, participants with TBI reported significantly greater problems with isolation and communication difficulties than those with other injury-related disabilities and significantly greater problems with written communication than those with other orthopedic injuries. One concern this finding raises is that the accuracy of reports by those with TBI may be questioned because of communications difficulties, the sixth highest ranked problem for this group. This concern is mitigated somewhat by the fact that many of these respondents held driver's licenses and would have had to pass written tests to maintain them. As such, these data on secondary conditions among those with TBI may not reflect the broader population who has more significant disability from TBI. Future research should address methods for collecting data on the experience of secondary conditions from those with significant cognitive impairment.

Overall, the level of income is striking, especially when it is considered with the employment rates reported. The median income for a household of two was only \$11,000 (compared to a per capita income of \$15,067 for the same period). Only 13% of the sample worked full- or part-time. As

such, many in this sample may experience problems associated with poverty that can exacerbate problems associated with functional impairments and contribute to the advent of disability. Thus, the relationship between employment, income, and secondary conditions deserves further attention.

Despite including people from very different populations (e.g., ILC consumers, American Indians, holders of permits, etc.), respondents shared many of the most problematic secondary conditions. Eight of the top 12 problems identified (e.g., depression) by consumers included problems for which wellness and lifestyle management techniques have been demonstrated as useful interventions. These issues tend to fall within three areas suggestive of prevention strategies.

First, wellness and health promotion strategies may be used to directly address problems in physical conditioning, isolation, and weight control. In addition, wellness promotion may address problems of fatigue, sleep disturbances, and depression, both directly and indirectly.

Second, behavioral management procedures may be used to directly address problems of chronic pain, sleep disturbances, depression, and fatigue. Both strategies may easily be used in an educational framework that is designed to help adults with disabilities exert more control over their lives and health status.

Third, access problems (e.g., lack of accessible buildings) were a leading issue. Access is a basis for social activity and meeting personal needs. Restriction of access may affect independence and health both directly and indirectly. Efforts to improve general community access might prevent or reduce the severity of many of the other secondary conditions reported.

These data point toward broad interventions to address common conditions, but they also suggest that research might profitably address problems that are less prevalent but that are reported as more severe by those experiencing them. For example, relatively few people with SCI experience care-related injuries but, when experienced, these injuries appear as the most severe for this population. Such problems may be amenable to preventive intervention with great benefit.

Self-management and environmental interventions may be particularly useful in such rural states as Montana, where access to specialized services can be difficult for many people with disabilities. Such interventions may also be more compatible with rural notions of personal responsibility.

Disability, defined as an inability to achieve one's goals and fulfill roles, is not an inevitable consequence of injury pathology or impairment. Additional research might develop methods for risk assessment for secondary conditions. Such methods would help target interventions for risk reduction and may assist individuals with disabilities to evaluate and manage their own health.

Programmatically, there is a need to develop and demonstrate models for preventing secondary conditions that are experienced by adults with disabilities living in the community independently. One approach is to integrate people with disabilities systematically into general health promotion activities. A second approach is to provide health promotion information and services through community-based disability services organizations such as ILCs. A third and more generic strategy is to support disability advocates' efforts to increase access to all areas of US society by people with disabilities.

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