The Stockholm spinal cord injury study: 4. Psychosocial and financial issues of the Swedish annual level-of-living survey in SCI subjects and controls

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In a series of articles from the Stockholm Spinal Cord Injury Study (SSCIS), the health status of a near-total regional SCI population comprising 353 subjects has been investigated. The present study describes the psycho-social and financial consequences of SCI in this group. It is based on a level-of-living survey that has been used annually on 8000–14 000 Swedes since 1974. The health-focused version of this survey was used for data collection in the subset of 326 subjects in the SSCIS that were residents of the Greater Stockholm area. The normative material consisted of 1978 interviews of residents of the same area, provided by the Swedish Bureau of Statistics. The results show that SCI subjects, although provided with basic material commodities up to par with the general population, have less financial reserves and more frequently express worry about their finances. Less than half of the subjects are gainfully employed, when part-time jobs are also included. Social activities are more restricted, and more centered on the core social network. Several items in the survey point to a preoccupation with personal rather than public matters.

We feel that these factors, at least to some degree, are consequential to separation from the workplace, with resulting disadvantageous financial and social effects. Intensified vocational rehabilitation efforts might thus be justified from both an economic and a psycho-social point of view.

Keywords: spinal cord injury; epidemiology; outcome; complications

Introduction

Due to the drastically improved prognosis *quo ad vitam* in the latter part of the 20th century for individuals with traumatic SCI, the issue of aging with SCI, and its long-term management, has emerged as a field of particular relevance. Medical, psycho-social and financial aspects need to be addressed, as well as the interplay between them. Several publications deal specifically with this subject, and give an exhaustive review of research done so far.^{1,2,3,4}

The Stockholm Spinal Cord Injury Study (SSCIS) emerges from the establishment in 1991 of a regional SCI Outpatient Clinic, covering subjects with chronic spinal cord or cauda equina lesions of traumatic aetiology. In the preparations for the launching of this service, a thorough search was made for identification of all persons with traumatic SCI living in the regional catchment area. The steps in this search procedure has been previously described.⁵ In a total regional population of close on 1.7 million, 379 people with traumatic SCI were identified. Of these, 93% (353

subjects) participated in the SSCIS. This study provides information about living with SCI from a different angle than do most previous studies. It is depicting a near-total prevalence population, also including ASIA/IMSOP Impairment Grade E-rated subjects and those that, for some reason or another, very seldom or never attend for medical follow-up. Thereby, the SSCIS hopefully can add to the knowledge of the natural history of this condition. On the other hand, its design does not allow provision of information about morbidity in the acute, pre- and intrahospital stage, neither information about mortality. These important issues, however, have been investigated by others.^{6,7,8} Thus, the SSCIS attempts to elucidate the impact of SCI as it is reflected in medical, psycho-social and financial status of a near-total prevalence-based population. Indicators of risk or vulnerability are sought, both in comparisons between the SCI group as a whole and a normal population, and within the SCI group, by assessment of sub-groups defined by basic clinical patient descriptors, such as gender, age at injury, and extent of the neurological lesion. In the previous papers from the SSCIS,^{5,9,10} we have reported on the frequent

occurrence of diverse medical problems among chronic SCI subjects. The core problems are both the ones that directly relate to impaired neurological function, for example as reflected in severe spasticity, sexual dysfunction, incontinence, neurogenic pain and neurological deterioration, and problems of more complex aetiology, for example non-neurogenic pain, constipation, fatigue and sleep disturbance. Generally, the increased health problems found in SCI subjects seem to be related mostly to the spinal lesion and its consequences, rather than to concurrent but unrelated morbidity. Moreover, significant quantitative as well as qualitative differences in morbidity profiles are found within the SCI population. These may indicate specific increases in vulnerability for certain problems associated with, eg, certain constellations of neurological compromise, gender and/or age at injury.

In the present report, we focus on issues related to psycho-social and financial aspects of SCI. The key question here is whether/how chronic SCI is associated with changes in psycho-social and financial parameters, i.e. social network, leisure activities, employment, organisational activities and sources of distress, as compared to normal material.

Subjects and methods

The SSCIS population included 353 SCI subjects living in the Greater Stockholm area and the island of Gotland, i.e. within the catchment area of the regional SCI services. The methodology utilised for identification of the study group, as well as its characteristics, has been published previously.^{5,9} Since Gotland represents a distinctly rural area, in contrast to the rest of the catchment area which is urbanised, these regions were considered separately. However, the number of subjects from Gotland were too few to allow a separate statistical analysis. Thus, only data from the subset of the 326 non-Gotland residents, 262 males and 64 females, were included in the analysis, and are presented herein.

The so-called Swedish Annual Level-of-Living Survey (Undersökning av Levnadsförhållanden, ULF) was chosen as investigative instrument. These surveys are based on nation-wide samples of the whole population in the ages 16–84 years, and have now been in use for 21 years. Each annual sample comprises 8000–14 000 individuals. Information as regards development of the surveys, quality issues, as well as technical issues is given elsewhere.^{10,11,12,13,14,15}

The survey of the study group was conducted by the SCI Clinic social worker, according to the training programme on the ULF, provided by the Swedish Bureau of Statistics. The interviewer followed a structured protocol, where straight-forward questions were given in a standardised manner. The interviewer was not allowed to elaborate on the questions or answers, but was instructed to adhere strictly to the protocol. The average time for completion of the interview was set at 60 min in a single session.

The control material consisted of 1978 interviews (960 males, 1018 females) made by the Swedish Bureau of Statistics in 1988–89 according to the health-centered ULF used in these years. The controls represented persons living in the same region as the study population, i.e. the Greater Stockholm area.¹⁶

Transfer of data to computer medium was made by staff at the Swedish Bureau of Statistics.

Statistical methods

Due to some differences in age and sex distribution between the study group and the normal material, with younger males dominating the SCI group, a statistical method for controlling these variables was imposed. Additionally, information regarding the socio-economic background was provided in the ULF survey, by data relating to parental socio-economic status. Such factors may have a profound influence on the variables under study. The socio-economic status of the *subject*, however, is possibly affected by the SCI and therefore a potential indicator of the consequences of the SCI rather than a confounding factor. Therefore, matching was made based on parental socio-economic situation. The indicator variable for this in the ULF is the occupation of the parent with the highest education.

For the comparison of proportions, i.e., the presence of a given factor amongst SSCIS individuals in comparison to the normative sample, the odds ratio was used as an estimation of association.¹⁷ The odds ratio is a measure of 'relative risk', calculated by the quote of the odds for the SCI group and the corresponding odds for the control group. In addition, due to the demographic differences between these samples regarding age and sex distributions as well as socio-economic background, it was decided to estimate an 'adjusted odds ratio', where these 'covariates' are statistically controlled for. This estimation was computed in a multivariate logistic regression analysis.¹⁸ Here, weights are assigned to independent variables, in such a way that the prediction of a given event (i.e., the binary dependent variable) is maximised. The regression weights can be converted into and then be interpreted as odds ratios, quantifying the partial association of a risk variable with the occurrence of a given item. In the present study, age, sex, socio-economic background, and SSCIS *vs* normative group membership were concurrently used to predict occurrence of specific attributes. In these multivariate analyses we were particularly interested in the regression weight assigned to the SSCIS/normative group membership variable. We have labelled this coefficient the 'adjusted odds ratio' because it is an odds ratio statistically adjusted for the concurrently predictive effects of age, sex and socio-economic background.

The exact *P*-values have been given in order to allow judgement in terms of type I errors.

Results

Material resources

Table 1 depicts the absolute frequencies in access of certain material resources in SCI subjects, and odds-ratios when comparing with the normative material. Generally, SCI subjects thus report:

- as good access to home and leisure facilities, for example bath, dish washer, freezer, TV, telephone, car, boat, camper, and summer house, as controls

- more access to video machine, but less access to daily newspaper
- inferior financial reserves as manifested in less access to reserve capital, more problems in managing running expenses, and more often living in multi-household, rented buildings.

Social network

Table 2 shows issues related to family, friends and social networks. It can be seen that SCI subjects have:

Table 1

Access to:	SCI %	Odds-ratio	p	SCI/controls Adjusted odds-ratio	p
Shower or full bath	99	2.30	0.2552	2.53	0.2129
Dish washer	46	1.06	0.6180	0.99	0.9183
Freezer	95	2.52	0.0003	2.82	0.0001
Phone	98	0.39	0.0780	0.49	0.2144
TV	98	1.62	0.1996	2.10	0.0548
Video	76	2.80	0.0001	2.63	0.0001
Daily newspaper	61	0.54	0.0001	0.53	0.0001
Balcony or patio	90	1.61	0.0175	1.66	0.0134
Car	76	0.99	0.9289	0.86	0.3030
Boat	6	1.06	0.8169	0.87	0.6137
Camper	20	0.86	0.3173	0.77	0.0908
<i>General financial status</i>					
Residence: condo vs house	67	1.47	0.0020	1.56	0.0007
Residence: rent vs own	61	1.81	0.0000	1.94	0.0000
Financial problems	21	1.70	0.0005	1.73	0.0007
Cannot raise 1200 USD equivalent to 9000 SEK	18	1.54	0.0074	1.74	0.0010

Table 2

Social network	SCI %	Odds-ratio	p	SCI/controls Adjusted odds-ratio	p
Parents alive	75	1.35	0.0314	1.00	0.9983
Sees parent often	42	1.07	0.6240	1.23	0.1780
Telephone contact with parent: often	72	0.82	0.2204	1.02	0.9260
Children outside household	39	1.19	0.1751	1.23	0.1962
Sees children often	58	0.80	0.2922	0.97	0.8836
Telephone contact with children: often	73	0.60	0.0231	0.91	0.7085
Has close friend	75	0.61	0.0006	0.77	0.0837
Sees friends often	68	1.68	0.0001	1.92	0.0001
Mutual help with neighbours	50	0.51	0.0001	0.52	0.0001
Sees neighbours	46	0.65	0.0004	0.65	0.0006
<i>Leisure and vacation</i>					
<i>During the last year:</i>					
Hiked	53	0.21	0.0001	0.19	0.0001
Other exercise walks	65	0.26	0.0001	0.26	0.0001
Been to the movies	52	0.56	0.0001	0.48	0.0001
Been to the theater	35	0.47	0.0001	0.50	0.0001
Been out to dinner	88	1.34	0.1039	1.27	0.2174
Attended religious services	18	0.59	0.0007	0.63	0.0037
Attended evening class	26	0.88	0.3641	0.88	0.3747
Been on vacation > 1 week	61	0.44	0.0001	0.41	0.0001

- similar amounts of contacts with their parents and children as controls
- more contacts with friends
- less contacts with neighbours.

Leisure activities

Table 2 further depicts engagement in leisure activities. SCI subjects generally report:

- less engagement in specific leisure activities, for example hiking and other outdoor activities, travel, going to the movies, theater and attending religious services.

Employment and work-related issues

Over 70% of SCI subjects received sick-pension (Table 3). Only 27% were gainfully employed on a full-time basis. Part-time employment was more common among subjects than controls.

When gainfully employed subjects and controls were being asked about working conditions, SCI subjects more often reported working with computers, and less often working in dirty (manual) labour (Table 4).

Organisational activities

Table 5 shows participation in various organisational activities. The SCI subjects differed significantly from

controls, in that the former were less involved in labour unions, but more involved in disabled organisations. Significantly fewer SCI subjects used their right to vote in government elections.

Sources of distress

Table 6 deals with sources of concern and distress. SCI subjects were more worried about their health and private financial situation than controls, and conversely less worried about local and global pollution.

Discussion

It should be noted that while the survey of the normative material was conducted in 1988/89, the SCI group was interviewed in 1991–1994. Changes in society during these years might account for at least part of the observed differences between the groups. However, to our knowledge, no major changes occurred in Sweden during these years that would influence the results significantly. This is further corroborated by the fact that no major changes have been noted in the ULF surveys of the general population in these years.¹⁹

It is important to stress the strongly developed social security system in Sweden. Almost all health care is public, and is financed through the tax system. Government funds cover the absolute majority of the

Table 3

<i>Employment last week</i>	<i>SCI</i>	<i>Odds-ratio</i>	<i>p</i>	<i>SCI/controls</i>	
	<i>%</i>			<i>Adjusted odds-ratio</i>	<i>p</i>
Full-time employee	27	0.30	0.0001	0.19	0.0001
Part-time employee	19	1.32	0.0695	1.64	0.0032
Self-employed	8	0.95	0.8075	0.67	0.0834
Searching for job	5	4.49	0.0001	4.51	0.0001
Pension	71	11.40	0.0001	53.50	0.0001
Student	7	0.63	0.0392	0.83	0.4553

Table 4

<i>Questions to gainfully employed</i>	<i>SCI</i>	<i>Odds-ratio</i>	<i>p</i>	<i>SCI/controls</i>	
	<i>%</i>			<i>Adjusted odds-ratio</i>	<i>p</i>
Safe job	92	1.92	0.0344	2.15	0.0156
Work-related accident last year	7	1.19	0.6035	1.14	0.6920
Stressful job	57	0.68	0.0231	0.66	0.0171
Monotonous job	16	1.22	0.3901	1.44	0.1263
Psychologically demanding job	32	0.71	0.0495	0.65	0.0208
Repetitive monotonous movements	36	1.27	0.1795	1.59	0.0131
Awkward work positions	26	0.69	0.0575	0.75	0.1369
Physically demanding job	16	0.95	0.8304	0.91	0.6792
Exposed to strong shaking/vibrations	6	0.94	0.8733	0.64	0.2328
Dirty work	22	0.61	0.0146	0.55	0.0046
Computer monitor job	63	2.88	0.0001	2.76	0.0001
Socialise with job mates	49	0.86	0.3857	0.86	0.4078

Table 5

<i>Organisational activities</i>	<i>SCI %</i>	<i>Odds-ratio</i>	<i>p</i>	<i>SCI/controls Adjusted odds-ratio</i>	<i>p</i>
<i>During the last year:</i>					
<i>Attended meeting(s) in</i>					
Labour union	17	0.55	0.0001	0.41	0.0001
Sports club	21	1.28	0.0987	1.07	0.6825
Camping assoc.	3	0.88	0.7127	0.72	0.3593
Senior citizen assoc.	2	0.38	0.0235	0.71	0.4623
Co-operative organisation	1	0.14	0.0068	0.15	0.0101
Condo assoc.	15	0.75	0.0828	0.71	0.0407
Disabled assoc.	21	18.52	0.0001	18.75	0.0001
Other assoc.	20	1.04	0.8096	0.92	0.5729
Member of Labour Union	48	0.73	0.0085	0.54	0.0001
Active	13	0.78	0.3304	0.70	0.1719
Member of political party	8	0.80	0.3144	0.74	0.1915
Active	23	0.67	0.4510	0.68	0.4924
Member of other assoc.	69	1.23	0.1120	1.15	0.2850
Active	49	1.26	0.1095	1.11	0.4753
Used right to vote in latest elections	82	0.44	0.0001	0.46	0.0001

Table 6

<i>Sources of distress</i>	<i>SCI %</i>	<i>Odds-ratio</i>	<i>p</i>	<i>SCI/controls Adjusted odds-ratio</i>	<i>p</i>
Private economy	41	2.33	0.0001	2.32	0.0001
Own health	43	2.13	0.0001	2.08	0.0001
Local environment pollution	38	0.62	0.0001	0.62	0.0002
Global environment pollution	76	0.45	0.0001	0.51	0.0001
International state of affairs	48	0.95	0.6472	1.16	0.2398

necessary equipment and adjustments judged necessary in housing, transportation, workplace and daily life activities. It seems reasonable to assume that the material prerequisites in our country for reintegration in society of SCI patients is up to par, if not exceeding, the rest of the Western world.

When interpreting the results of the present study, SCI subjects in Sweden seem to have equal access to basic material commodities as compared to the general population. Such equipment and commodities are generally financed through the social security system for the disabled. They therefore do not reflect the private economy of the disabled individual. On the other hand, the financial reserves are more sparse in the SCI group. This is understandable, since many individuals in this group rely on sick pension as their main source of income.

The finding of a lower access to a daily newspaper can hardly be explained by lack of financial resources, since the access to video exceeds that of the normal population. It may instead be interpreted as a sign of relative disinterest for public life within the SCI population.

Contacts within the core social network, i.e. parents, children and friends, are at least as frequent

in SCI subjects as in the normative population. In fact, contacts with friends are almost twice as frequent within the SCI group. In contrast, contacts outside the core social network are more restricted, as is reflected in less contacts with neighbours, and less engagement in specific leisure activities. Surprisingly, only 21% of SCI subjects are engaged in organisations for the disabled. Although this is more common than in the general population, as can be seen from our results, one would perhaps have expected a higher participation rate in a patient group with such a substantial disability. Furthermore, less than 50% of SCI subjects are gainfully employed, and many of those only on a part-time basis, despite the majority being in their productive years. This probably adds to the restricted contacts outside the sphere of family and friends.

When evaluating sources of distress, it becomes clear that SCI subjects are significantly more concerned with their own financial and health situation, and less concerned with local and global environmental pollution than controls. Also, significantly fewer SCI subjects used their right to vote in the most recent government elections. Again, this might be interpreted as a sign of disinterest in public matters.

Data from the National SCI Database in USA,²⁰

show peak post-injury employment rates of just over 30% 10 years after injury. The so-called PSA-DIS survey, also from USA,²¹ describes the impact of SCI on, among other things, life style by comparing the time spent on activities before injury with the time spent on activities post-injury. Here, the majority of the SCI population was found to have significantly changed their time allocation as a result of the injury. In particular, a major shift occurred between the time spent on social activities and the time spent on personal care activities, the latter increasing at the expense of the former. The PSA-DIS survey also included estimations of annual earning losses after SCI, which for all cases was estimated to over 12 000 USD annually.²¹

Thus, in the crucial areas of employment, personal finances and time allocation for SCI individuals, the trend is largely similar in Sweden and USA.

In summary, SCI subjects in our region seem to have a normal basic standard of living, but a relative lack of financial reserves becomes evident from several items in the survey. Contacts and activities are more restricted, and are proportionally more centered on the core social network. Interests and concerns are more focused on the private rather than public matters. Many SCI subjects are not gainfully employed. Taking into consideration the traditionally strong public health care system in Sweden, as well as the extensive financial support already provided by the government, it seems unrealistic, and probably inefficient, to rely on additional public financial support to achieve further psychosocial or financial improvements in the SCI group. It can surely be debated, whether the overall situation as depicted in this study should be judged as 'good' or 'bad', and thus if the present situation calls for any action at all. Leaving this complex question aside, we however feel that further financial improvement and reintegration in society is desired for SCI survivors, and that efforts to increase the proportion of persons in gainful employment is the most realistic option to achieve that goal.

Acknowledgements

This study was supported by The Spinalis Foundation, the Swedish Medical Research Council (grant 06555), Allmänna Arvsfonden and The Swedish National Board of Health and Welfare. The authors thank Ms Susanne Wikblad for excellent secretarial help, Ms Åsa Llinares for performing the interviews, and Mr Petter Gustavsson, MSc, for statistical assistance.

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