

Original Article

Health behaviour of persons with spinal cord injury

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Study design: Postal survey.

Objective: To describe the health behaviour of persons with spinal cord injury (SCI) living in the community and the relationships between health behaviour, respondent/injury characteristics, and health-related variables: the presence and number of secondary impairments, readmissions in rehabilitation centre and hospital, and perceived health.

Setting: Members of the Dutch Association of Patients with SCI.

Methods: The frequency of health behaviours, that delay or prevent secondary impairments, was assessed by means of a 22-item, self-report questionnaire. The questionnaire was also focused on 13 secondary impairments.

Results: The frequency of engaging in health behaviour varied considerably between the respondents. Variance was observed between and within the health behaviours measured. The respondents did not frequently engage in pressure relief methods when sitting/driving in their wheelchair. Almost no statistical differences were observed between health behaviour of subgroups of respondents based on respondent/injury characteristics. However, the total health behaviour scores increased significantly with increasing age and pressure sore prevention was significantly more applied in persons with a complete lesion. Health behaviour was significantly more applied in respondents who had one or more secondary impairments.

Conclusion: As secondary impairments are prevalent among persons with SCI and education on a healthy lifestyle is a core component of every rehabilitation programme, it is of great importance to rigorously test the efficacy of health behaviours promoted during rehabilitation. Therefore, longitudinal research is recommended.

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Introduction

A spinal cord injury (SCI) very often results in an everlasting complete or incomplete muscle paralysis, sensory loss, and autonomous dysfunction below the level of the injury. During rehabilitation, patients receive education and training to give them sufficient skills and knowledge about the injury to deal with its consequences in daily life. Among other topics, much attention is paid to a healthy lifestyle and the prevention of secondary impairments.¹ However, persons with SCI, nevertheless, often experience secondary impairments after discharge from rehabilitation.^{2–9} In response to this observation, several Dutch rehabilitation centres have developed follow-up care interventions.¹⁰ Education and training about health maintenance and prevention also is an important component of these

interventions. In order to be able to evaluate the effectiveness of this education and training, it is important that the health behaviour of persons with SCI be assessed.

This study is aimed at describing the health behaviour of persons with SCI living in the community and the relationships between health behaviour and respondent/injury characteristics. The results should give insight into the health behaviour and differences in health behaviour that may exist in different groups of persons with SCI living in the community, and may help to distinguish for whom training and education regarding a healthy lifestyle is very important. The second aim was to describe the relationships between health behaviour and health-related variables: the presence and number of secondary impairments, readmissions in rehabilitation centre and hospital, and perceived health. Assuming that at least part of secondary impairments can be

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prevented, it might be expected that there is a negative relationship between 'good' health behaviour and the presence of secondary impairments. The better the health behaviour of persons with SCI, the fewer secondary problems they might experience. On the other hand, a positive relationship between good health behaviour and good perceived health was expected.

Methods

Data collection

A questionnaire was sent to all members of the Dutch Association of Spinal Cord Injured Patients. The questionnaire focused on health behaviour, secondary impairments, perceived health, and self-care ability.

Persons who were unable to write were invited to make use of a digital/computerised version of the questionnaire, which could be obtained on request. A reminder was sent 4 weeks after the questionnaire was mailed.

Health behaviour The Spinal Cord Injury Lifestyle Scale (SCILS) of Pruitt *et al*¹¹ was used as a basis for our health behaviour scale. The SCILS is a 25-item, self-report questionnaire designed to assess the frequency of behaviours specific to SCI health maintenance and behaviours that promote general health for the avoidance of secondary impairments. The SCILS was adapted, as some items were formulated rather generally (ie 'I am aware of and try to reduce my risk for heart disease'), and some items were not applicable for all persons with SCI (ie 'I change my catheters as often as I have been directed to'). Also some adaptations were needed to suit the scale to Dutch SCI rehabilitation practice.

A panel of clinicians (physiatrists, occupational therapists, physiotherapists, social workers, psychologists, and nurses), researchers, and experienced patients adapted the SCILS. Changes were made especially with regard to genitourinary health behaviour aspects. Initially, a list of 31 descriptions of health behaviours resulted, containing 10 items that also were included in the SCILS and 21 new items. For all items, the respondents were asked to state the frequency of occurrence (never, sometimes, often, always).

Using the data from our current study, the possibilities for item elimination and clustering of items into subscales were examined using a combination of content, reliability, and factor analysis (Principal Component Analysis with Varimax rotation). Forty-four out of 454 respondents had 10% or more missing values and were not taken into account in the analyses. Firstly, five items were eliminated because of lack of discriminative ability, as 85% or more of the respondents gave exactly the same answer to these items (topics were: frequency of having stool, finishing a cure of antibiotics, prevention of skin burns, having medicines and 'caring supplies' in stock, and the use of soft drugs). The factor analysis did not reveal distinctive and reliable

subscales, although there were eight items regarding the prevention of pressure sores with a reliability coefficient of 0.80 (see items 1–8 in Table 2). Reliability analysis led to a health behaviour scale consisting of 22 items (see Table 2) and elimination of four items on the basis of low (≤ 0.20) corrected item – total correlations (topics were: standing and walking exercises, bladder emptying, abstinence from smoking, and use of alcohol). Cronbach's alpha for the 22 items was 0.80, implying that the items were interrelated and measure the same underlying construct, that is, preventive health behaviour.

The scores of each item were summarised using 0 for 'never', 1 for 'sometimes', 2 for 'often', and 3 for 'always'. A total health behaviour score was calculated by summing up the scores of each item. The total score range is from 0 (never performing any health behaviour) up to 66 (always performing all health behaviours).

Secondary impairments The questionnaire included questions about 13 secondary impairments: bladder problems, bowel problems, spasms, pain, oedema, pressure sores, increasing weight, excessive sweating, contractures, breathing/respiratory tract problems, neurogenic heterotopic ossification, low blood pressure, and thrombosis. For each secondary impairment, the respondents were asked to indicate whether or not they had faced this problem during the previous 12 months.¹² A sum score was computed indicating the number of secondary impairments (0–13).

Perceived health Perceived health was measured using the General Health scale of the SF-36.¹³ This scale consists of five questions about overall health, the person's own health compared to others, and one's vulnerability to becoming ill. The total score of this scale is between 0 (very poor health) and 100 (perfect health).

Self-care ability Self-care ability was measured using the Dutch questionnaire version of the Barthel Index (BI), the reliability and validity of which have been shown to be good.¹⁴ The BI rates the degree of independence from help by others in performing activities of daily living. It consists of 10 items concerning activities of daily living (bathing, dressing, feeding, toilet use, grooming, bladder, and bowels) and mobility: transfers, climbing stairs, and walking/wheelchair driving. The total score of the BI is between 0 and 20 and is interpreted as: 0–4 'very disabled', 5–9 'severely disabled', 10–14 'moderately disabled', 15–19 'mildly disabled', and 20 'independent'.¹⁴ In our sample, the reliability of the BI was high (Cronbach's alpha 0.85).

Statistical analysis

Description of health behaviour To describe the health behaviour of the respondents, descriptive analyses were

used. Total health behaviour scores were calculated for the following subgroups:

- Male *versus* female.
- Tetraplegia (C1-T1) *versus* paraplegia (T2-S5). The self-reported highest motor level was taken as the level of injury.
- Complete *versus* incomplete injury. Some respondents reported a complete injury together with a partial injury at a higher level; in the analysis they were treated as having a complete injury.
- Duration of injury was trichotomised: 0 till 5 years (about 25% of the respondents), 5 till 19 years (about 50%), and over 19 years (about 25%).
- Age of injury was trichotomised: 18 till 35 years (about 25% of the respondents), 35 till 55 years (about 50%), and over 55 years (about 25%).

To describe the health behaviour in relation with health-related variables, the respondents were grouped as follows:

- The number of secondary impairments was trichotomised. Grouping was: 0 till four impairments (about 25% of the respondents), 4 till six impairments (about 50%), and over six impairments (about 25%).
- The presence of bladder problems, bowel problems, pain, spasms, and/or pressure sores during the past 12 months. These problems had been identified as being the most important secondary impairments in persons with SCI.¹²
- Experienced general health was trichotomised. Grouping was: 18 till 45 (about 25% of the respondents), 45–75 (about 50%), and over 75 (about 25%).
- Being readmitted in a rehabilitation centre since primary rehabilitation or not.
- Being readmitted in a hospital since primary rehabilitation or not.

Associations The health behaviour score was treated as a variable of ordinal level. To detect associations between health behaviour, respondent/injury characteristics, and health-related variables, Mann–Whitney *U*-tests and Spearman correlations (age, duration of SCI, number of secondary impairments, perceived health) were calculated. The level of statistical significance was set at $P < 0.05$.

Results

Respondents

The questionnaire was sent to 997 members of the patient association, of whom 454 responded (45.5%). There were 410 respondents, who had less than 10% missing values in the 31 health behaviour items. Table 1 shows their general characteristics. Time after injury varied between half a year and 62.6 years, and age

Table 1 Subject characteristics ($N = 410$)

Age, mean (years) (SD)	46.9 (13.2)
Time since injury, mean (years) (SD)	13.6 (10.7)
Married or cohabitating (%)	64.9
Living on one's own (%)	25.6
Gender, male (%)	66.1
<i>Level and type of injury (%)</i>	
Complete tetraplegia	21.0
Incomplete tetraplegia	13.1
Complete paraplegia	47.9
Incomplete paraplegia	17.9
<i>Cause of injury (%)</i>	
Traffic accident	34.0
Sports, recreation	19.7
Fall	9.6
Accident at working place	8.4
Gunshot or stab wounds	0.2
Medical interventions	8.4
Disease	9.4
Other	10.3
<i>Barthel Index, mean (SD)</i>	
Total group	12.1 (4.6)
Complete tetraplegia	8.3 (4.4)
Incomplete tetraplegia	9.4 (5.1)
Complete paraplegia	13.6 (3.2)
Incomplete paraplegia	14.3 (3.8)

varied between 18 and 82 years. Only eight respondents used the digital/computerised version of the questionnaire. The response group could not be compared with the nonresponse group regarding the characteristics mentioned in Table 1, as these data were not available.

Health behaviour and relationships with respondent/injury characteristics

Table 2 presents the scores on all 22 items. There were four health behaviours that were often or always applied by more than 85% of all respondents. These were 'skin care in case of incontinence' (item 8), 'examination of the cause of pressure sores' (item 4), and 'taking the (right amount of) prescribed medicines' (items 18 and 19). The least applied health behaviours were 'monitoring blood pressure' (item 17), 'limiting fat and cholesterol intake' (item 16), and 'pressure relief methods like weight shifts' (item 3). More than 80% of the respondents did not check their blood pressure on a regular basis and more than half of the respondents almost never engaged in the health behaviours items 3 and 16. The percentage of respondents that 'often' or 'always' engaged in the remaining health behaviours varied from 61.4 to 79.7. In sum, the scores within and between the items varied considerably.

Table 3 presents the median total scores for the whole group of respondents and for subgroups based on respondent/injury characteristics. Few differences were observed between health behaviour of subgroups of respondents. However, the total health behaviour scores increased significantly with increasing age (Spearman correlation 0.24). Pressure sore prevention (items 1–8)

Table 2 Health behaviour scale and health behaviour scores per item ($n=410$)

Items	Never (%)	Some times (%)	Often (%)	Always (%)
(1) I take care not to develop skin breakdown or areas of redness, when I am sleeping	11.3	16.2	13.5	59.0
(2) I check my skin daily on areas of redness or breakdown or I have checked my skin daily	10.0	28.6	21.3	40.1
(3) I do some type of pressure relief every 30 minutes any time I am sitting or driving in my wheelchair (by changing my position or lifting myself)	22.9	29.7	26.5	20.9
(4) If I have a skin breakdown, I would try to find out how it occurred	4.4	8.9	12.3	74.3
(5) I am careful not to bump my legs, feet, or buttocks when doing transfers	7.8	12.5	22.3	57.4
(6) I am aware of the condition of my anti-pressure sores devices	11.7	16.3	25.3	46.7
(7) If I have a skin breakdown/pressure sore, I would be careful not to put weight on it (I would not sit or lie on it)	9.6	18.0	20.6	51.8
(8) In case of incontinence, I would take care to have my skin dried as soon as possible	3.2	5.7	17.6	73.4
(9) I am careful to keep my joints flexible (I regularly do range of motion exercises or have these exercises done)	12.2	18.6	25.2	44.0
(10) I do exercises that enhance my muscle strength (possibly with help of my physiotherapist)	12.7	18.5	26.8	42.0
(11) If my urine looks turbid or smells, I would have it examined	11.1	24.8	17.2	46.9
(12) I drink at least 2 litres a day	5.1	21.0	27.6	46.3
(13) In case I have symptoms of autonomic dysreflexia (sweating, headache, red complexion, and high blood pressure), I would examine why I have these symptoms (e.g. full bladder, full bowel or clothes that are too tight)	17.1	13.4	18.4	51.1
(14) In case of 'hard' stool, I take care to drink more, to eat more fibres or take more laxantia	12.5	13.8	16.5	57.2
(15) I take care that my weight doesn't increase	9.3	23.2	32.4	35.1
(16) I limit the amount of fat and cholesterol in my diet (for example, I limit red meats, dairy products)	29.3	25.1	29.8	15.9
(17) I monitor my blood pressure on a regular basis or I have it monitored regularly	51.0	32.0	11.7	5.4
(18) I always take the medicines that are prescribed	1.5	4.4	15.6	78.5
(19) I always take that amount of medicines that is prescribed	1.7	4.0	16.9	77.4
(20) In case I have physical complaints I would consult a doctor (e.g. in case of skin breakdown, bladder infection, pneumonia, a changing level of spasms, increasing symptoms of autonomic dysreflexia, or an increasing level of pain)	1.5	23.4	28.3	46.8
(21) I will always make clear my wishes regarding the way I would like to receive care	2.2	11.1	23.0	63.7
(22) When I leave my home, I always take my medicines and/ or 'caring supplies' with me	6.1	10.8	13.5	69.5

Range per item 0–3 (never–always)

was significantly ($P<0.01$) more implemented by persons with a complete lesion (median sumscore items 1–8: complete lesions 19.0, incomplete lesions 16.0).

Health behaviour and relationships with health-related variables

Table 4 presents the prevalence of secondary impairments investigated. On average, the respondents experienced 4.6 secondary impairments. The most frequently

occurring secondary impairments were: bladder and bowel problems, spasm, pain, and oedema. Only six respondents (1.5%) experienced no secondary impairments at all.

Table 5 presents the health behaviour scores in relation with health-related variables. Most times, the total health behaviour scores were slightly higher for respondents in poorer health. A significant but weak correlation (0.17) existed between the number of secondary impairments and the total health behaviour

Table 3 Health behaviour in relation with respondent/injury characteristics (*n* = 410)

	Median total score
Median total score	46.0
Interquartile range	12.3
Range	18–66
Gender	
Man	47.0
Woman	45.0
Level of injury	
Tetraplegia	48.0
Paraplegia	46.0
Type of injury	
Complete injury	47.0
Incomplete injury	44.0
Duration of SCI (years)	
≤ 5	47.0
5–19	46.0
> 19	46.0
Age (years)	
≤ 35	43.0*
35–55	47.0*
> 55	48.0*

P* < 0.01Table 4** Experienced secondary impairments during the previous year (*N* = 410)

	<i>N</i>	%
Bladder problems (eg incontinence, urinary tract infections)	297	72.4
Bowel problems (eg incontinence, diarrhoea, constipation)	254	62.0
Spasms	234	57.1
Pain	224	54.6
Oedema (accumulation of liquid in the legs)	204	49.8
Having pressure sores or preventing problems	154	37.6
Increasing weight	125	30.5
Excessively sweating	113	27.6
Contractures (decreased joint mobility due to reduction of muscle length)	93	22.7
Breathing/respiratory tract problems (eg shortness of breath, infection of respiratory tract)	78	19.0
Calcification or the growth of bone around joints below the level of the injury (neurogenic heterotopic ossification)	53	12.9
Low blood pressure	46	11.2
Thrombosis (blood clots in blood vessel)	14	3.4

score. The more secondary impairments respondents had, the better their health behaviour scores were. Significant relationships also existed between the presence of pressure sores and the total health behaviour score and the sumscore of the pressure sore prevention health behaviours (median sumscore items 1–8: no pressure sores 17.0, pressure sores 19.0, *P* < 0.01). Health behaviour was significantly more frequently implemented by respondents who had been readmitted

Table 5 Health behaviour in relation with health-related variables (*n* = 410)

	Median total score
Median total score	46.0
Interquartile range	12.3
Range	18–66
Number of secondary impairments in previous 12 months	
< 4	44.0**
4–6	46.0**
> 6	48.0**
Secondary impairments in previous 12 months	
No pressure sores	45.0*
Pressure sores	48.0*
No bladder problems	47.0
Bladder problems	46.0
No bowel problems	45.0
Bowel problems	47.0
No pain	46.0
Pain	47.0
No spasm	47.0
Spasm	46.0
Not readmitted in rehab centre since primary rehabilitation	46.0
Readmitted in rehab centre since primary rehabilitation	47.0
Not readmitted in hospital since primary rehabilitation	44.0*
Readmitted in hospital since primary rehabilitation	47.0*
General health SF-36 range 0–100	
≤ 45	48.0
45–75	45.0
> 75	45.0

***P* < 0.01**P* < 0.05

in a hospital since their primary rehabilitation. There was no significant relationship between health behaviour and perceived health.

Discussion

This study shows that the frequency of applying health behaviour by persons with SCI living in the community varies considerably between individuals. Variance was observed between and within the health behaviours measured. In our opinion, it is notable that the respondents did not frequently apply pressure relief methods when sitting/driving in their wheelchair (item 3). The importance of this health behaviour is emphasised during clinical rehabilitation. Pressure sore prevention was significantly more applied in persons with a complete lesion. Probably this is explained by the fact that persons with complete lesions have a higher risk to develop pressure sores.^{4–6,15,16} It is also notable that the total health behaviour score tends to increase significantly with increasing age, although Pruitt *et al*¹¹ found no relationship between the total SCILS score and age.

Most striking are our results regarding the relationships between health behaviour scores and health-related variables. A negative relationship was expected between health behaviour and the presence of secondary impairments. The better the health behaviour of persons with SCI, the fewer secondary problems were expected. The present study shows the opposite: health behaviour scores were higher for respondents who had one or more secondary impairments. This may indicate that persons with secondary impairments modified their health behaviour to prevent these secondary impairments in future. Another explanation may be that the health behaviours as measured do not have much impact on the occurrence of secondary impairments. Some of the secondary impairments in our list are more likely to be influenced by health behaviour, for example, increasing weight or pressure sores, than others, for example, neurogenic heterotopic ossification or pain. It might also be that certain health behaviours are only relevant for persons 'at risk', for example, pressure relief might only be relevant for persons with complete injuries. Pruitt *et al*¹¹ also did not observe a positive relationship between health behaviour and the number of secondary impairments, whereas other researchers¹⁷⁻²⁰ demonstrated that there were no significant relationships between the occurrence of pressure sores and the traditional protective behaviours for pressure ulcers, such as weight shifts or skin checks.

The possible explanations for our observation that health behaviour was more frequently applied by persons with more secondary impairments are in sharp contrast with each other and lead to contrasting implications for rehabilitation practice. In case, health behaviour has a positive effect on the prevention of secondary impairments, but persons with SCI only tend to engage in it after the occurrence of secondary impairments, the attention for education and training on health behaviour should be intensified. Rehabilitation professionals then need to focus on developing effective methods of persuading persons with SCI to take more responsibility for their health behaviour and to deliver information and education at a time when persons with SCI feel ready for it and recognise the relevance.²¹ Currently, education is institutionally based and acute rehabilitation oriented. Rehabilitation professionals also might need to expand their education regarding health behaviour in the long-term to persons who are living in the community. In case that protective health behaviour is only relevant in persons 'at risk', there seems to be no need to teach everything to everyone but is it important to identify groups that are at risk for certain secondary conditions and to teach them the skills necessary to prevent these conditions. Also, the effect of education and resulting health behaviours should in that case only be tested in such specific risk groups. In case, health behaviour as measured does not have any impact at all on the occurrence of secondary conditions, it is not necessary to spend so much effort to the education on health behaviour during rehabilitation, implying immense

consequences for the content of most rehabilitation programmes.

Owing to the cross-sectional study design, it is not possible to say whether or not persons with SCI only started the health behaviour measured after the occurrence of problems. As education on a healthy lifestyle is a core component of literally every rehabilitation programme and secondary impairments are prevalent, it is of great importance to rigorously test the efficacy of health behaviours promoted during rehabilitation. Therefore, longitudinal research is recommended to study what persons with SCI know about health behaviour; when, why, and what health behaviours they practice; and the impact of health behaviour on the prevalence of secondary impairments.

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