

## ORIGINAL ARTICLE

# Health-related quality of life in persons with long-standing spinal cord injury

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**Study design:** A cross-sectional study of all patients with traumatic SCI admitted to Sunnaas Rehabilitation Hospital, Norway between 1961 and 1982.

**Objectives:** To assess health-related quality of life (HRQOL) in persons with long-standing traumatic spinal cord injury (SCI) in Norway.

**Setting:** Sunnaas Rehabilitation Hospital, Norway.

**Methods:** Survey data and clinical examination of 165 persons with traumatic SCI of more than 20 years duration. HRQOL was assessed with the Norwegian 36-item short-form social functioning (SF-36) Health Survey. The SF-36 results were compared with Norwegian norm data adjusted to age and gender. Differences in HRQOL between subgroups were studied.

**Results:** The persons with SCI exhibited significantly decreased HRQOL in the subscales for Physical Functioning, Bodily Pain, General Health and Vitality compared to the normal population. There were relatively small differences in HRQOL when comparing persons with paraplegia versus tetraplegia and persons with AIS (ASIA Impairment Scale; ASIA, American Spinal Injury Association) A–C versus D–E. Employed persons reported higher HRQOL compared to unemployed persons. HRQOL of individuals reporting health problems or symptoms was worse than those of individuals reporting no health problems at all.

**Conclusion:** HRQOL is decreased in persons with long-standing SCI and especially in persons with comorbidity conditions.

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## Introduction

As the longevity of persons with traumatic spinal cord injury (SCI) has improved, research has shifted focus from being primarily concentrated on the acute care or the first years after injury to increased interest in social and psychological adjustment to the SCI, quality of life (QOL) including health-related quality of life (HRQOL), long-term consequences and aging. Persons with SCI often experience complications and problems related to their disability.<sup>1,2</sup> Enhancing daily functioning and well-being are important goals in the treatment of persons with SCI, both at an early stage after injury as well as in persons with long-standing SCI. The impact of SCI on QOL is important information, especially for monitoring and organizing health-care services. Various

approaches to quantify QOL have been developed, depending on whether the focus is meant to be HRQOL, well-being or QOL as a superordinate construct.<sup>3–5</sup>

Measurements of HRQOL focus on the individual's satisfaction or happiness with domains in life that are affected by health or health care, and several assessment tools are available for this purpose. Recently, Ku<sup>6</sup> reviewed the Medical Outcomes Study 36-item short-form health status survey (SF-36) in patients with SCI. The author concludes that there is a lack of literature on comprehensive HRQOL issues for patients with SCI. He also suggests that the identification of factors affecting HRQOL may influence preventive, diagnostic and therapeutic strategies for the improvement of HRQOL in persons with SCI. Using the SF-36, studies of persons with SCI in Canada, the United States, Sweden and Australia have indicated significant reductions in HRQOL compared to general populations.<sup>7–11</sup> Most studies report that the greatest difference is seen in Physical Functioning (PF), and scores on Mental Health (MH) and Social Functioning (SF) diverge less from general

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population scores.<sup>10,11</sup> Older age, unemployment, hospitalization during the last year and various medical complications such as pain, spasticity and incontinence seem to have more negative effects on HRQOL than the level and extent of SCI as such.<sup>7,9</sup> However, the topic has been relatively little studied in European SCI populations, as well as in persons injured more than 20 years ago.

In the present paper we report the results of the first long-term follow-up assessment of HRQOL in SCI survivors in Norway, assessed with the Norwegian SF-36 Health Survey. The results are derived from a larger Norwegian investigation on persons who sustained traumatic SCI between 1961 and 1982. The intention with this study is to increase knowledge of how persons with SCI of long duration, living in a Scandinavian country, health care system and culture, perceive their HRQOL and to identify possible problem areas that need more attention in the long-term follow-up care. The results also provide valuable information for further studies. The main objective was to compare HRQOL of persons who sustained traumatic SCI more than 20 years ago with norm data from the general Norwegian population. Furthermore, we wanted to explore differences in HRQOL between subgroups within the study sample.

## Materials and methods

The study consists of all persons admitted to Sunnaas Rehabilitation Hospital after traumatic SCI between 1961 and 1982, and general population controls.

### SCI sample

A total of 237 persons were contacted by a mailed letter to request their participation in the study. For those who accepted to participate, data collection took place as follows: a set of questionnaires was mailed out, along with a stamped return envelope and a call-up notice for a personal interview. Then, a face-to-face interview (including response to the SF-36) and a clinical examination with ASIA Impairment Scale (AIS) scores (International Neurological Standards for Classification of Spinal Cord Injury)<sup>12</sup> were undertaken. Four persons were interviewed by telephone.

Retrospective information such as demographic data at the time of injury and injury-related data were obtained from archived medical records (including Frankel classification). Injury etiology was grouped according to the International Spinal Cord Injury Core Data Set.<sup>13</sup> The existing Norwegian rules attended to protect the privacy of the individual, demand an acceptance from each individual, respondents as well as nonrespondents, if any data from their medical journal are to be used. Therefore, a brief questionnaire was mailed out to all nonrespondents.

### General population controls

SF-36 data from the general Norwegian population ( $n=5152$ ) were obtained from the Norwegian Survey Archive, Norwegian Social Science Data Services.<sup>14</sup>

### Measures

The SF-36 is a self-report health questionnaire, and the most widely used generic HRQOL outcome measure.<sup>15</sup> It has been shown to be a valid and reliable instrument, translated into many languages, including Norwegian.<sup>16</sup> Norwegian normative values for the SF-36 have been published.<sup>17</sup> Further, the SF-36 has been evaluated for use in SCI populations, and its applicability has so far been described as acceptable.<sup>3,5,18</sup> The SF-36 contains eight individual scales: PF, Role Physical (RP), Bodily Pain (BP), General Health (GH), Vitality (VT), SF, Role Emotional (RE) and MH. Scores range from 0 to 100, where higher scores indicate better health status. The scales PF, RP and BP mainly measure physical components, while MH, RE and SF measure mental health. Individual scales can be transformed into a mental and physical summary scale.

In this study, HRQOL was assessed using the Norwegian SF-36 (version 1.2, chronic).<sup>16</sup> Because HRQOL varies according to age and gender,<sup>19</sup> the norm scores were adjusted to reflect age and gender distributions to those of the SCI participants. The mean scores of the SCI sample were compared to the adjusted norm data. The method was derived from Hjemstad *et al.*<sup>19</sup> Additionally, HRQOL was analyzed for subgroups within the SCI sample. Subgroups were defined from demographic information (gender, marital status, age at injury, region of residence), employment status, level (tetraplegia/paraplegia) and extent (AIS A–C/AIS D–E) of the SCI, and also according to perceived medical problems.

The participants answered an open question on currently perceived health problem(s). In the case of more health problems, they were asked to list problems as follows: main health problem, second worst problem and so on. For analytic purpose, perceived main problems were categorized into six groups, including the subgroup 'no health problem'. Further, the subgroups 'one health concern' and 'more health concerns' were established. Current employment status was categorized into 'employed' (paid work) and 'not employed' (students, unemployed, homemaker), and marital status as married/cohabitant versus single. Age at injury was dichotomized into  $\geq 21$  versus  $< 21$  years, and time since injury was divided into  $\geq 27$  versus  $< 27$  years. Region of residence at the time of the study was divided into 'living in central eastern Norway (including Oslo)' versus 'other region of residence'. Further, we defined two groups according to the time of injury, that is, between 1961 and 1975 and between 1976 and 1982. This was done because the SCI rehabilitation gradually became organized as a specialized unit with multidisciplinary teams from the early to mid 1970s.

The study was approved by The Regional Ethics Committee, Oslo, Norway.

### Statistical analysis

Descriptive statistics included proportions, means and standard deviation (s.d.).  $\chi^2$ -statistics were applied to compare categorical variables. The *t*-tests for independent samples and the Mann–Whitney *U*-tests were performed where appropriate.

HRQOL data were presented with means and s.d. Deviations in HRQOL from age- and gender-adjusted norm data were analyzed with one-sample *t*-tests. In addition we calculated effect sizes (ES) by using the *t*-value and degrees of freedom from the one-sample *t*-test.<sup>20</sup> Differences in HRQOL between subgroups within the SCI population were analyzed with independent samples *t*-tests. The ES was calculated as the difference between the two means divided by the s.d. corresponding to the largest comparison group. The levels of ES were interpreted as small (that is, 0.20), medium (that is, 0.50) and large (that is, 0.80).

Statistical Packages for the Social Sciences (SPSS) 13.0 was used for statistical analyses. *P*-values  $\leq 0.05$  were considered statistically significant.

## Results

### Population

A total of 179 individuals (76%) with SCI accepted to participate in the study. At the time of the study, five persons were inaccessible/could not be reached, five persons could not find time for participation and three persons deceased before the data collection took place. Another person was excluded due to incomplete data. Further, 35 out of 58 nonrespondents answered a brief questionnaire. They were significantly older at injury and at follow-up ( $P < 0.001$ ), and more nonrespondents had a functionally incomplete SCI than the study participants ( $P < 0.001$ ; for this comparison of participants versus nonrespondents we used Frankel classification described in their archived medical journals).

### Participant characteristics

The total number of participants was 165 (Table 1), of which 49% were living in the central eastern part of Norway (including Oslo). The characteristics did not differ between genders. Persons injured during the first period were younger at injury (mean 22 years, s.d. 9.9) versus those injured after 1975 (mean 25 years, s.d. 9.5) ( $P = 0.02$ ). A total of 79% of the participants reported health concern(s) (Table 2).

### HRQOL

A total of 162 persons answered the SF-36 questionnaire. The results are shown in Table 3, including comparison with SF-36 data from the general Norwegian population. Persons with SCI had significant lower scores with the subscales PF, BP, SF, VT and GH. The ES was large for the PF subscale. Medium ES was seen in the subscales BP and GH. In all other subscales the ES was small.

### HRQOL in subgroups

Table 4 shows the HRQOL for various subgroups including groups defined according to the self-reported health problems. Information on the groups 'my disability,' 'musculoskeletal problems' and 'other health concern(s)' was considered in the analysis but not shown in the table, because the ES in each subscale was small (data available on request).

**Table 1** Characteristics of participants

Category	Total (N = 165)
<b>Gender</b>	
Male, N (%)	135 (82)
Female, N (%)	30 (18)
Mean age at injury (s.d.)	23 (9.7)
Mean age at follow-up (s.d.)	50 (10.1)
Mean time since injury (s.d.)	27 (4.3)
Employed/not employed at follow-up (%)	35/65
Married or cohabitant at follow-up/ not married or cohabitant (%)	55/45
<b>Cause of injury (%)</b>	
Sports	16
Assaults	5
Transport	53
Fall	19
Others or unknown	7
<b>Impairment group (N = 161) (%)</b>	
Tetraplegia, AIS A–C	30
Tetraplegia, AIS D–E	5
Paraplegia, AIS A–C	55
Paraplegia, AIS D–E	10
<b>Self-reported health problem(s) at follow-up<sup>a</sup> (N = 160) (%)</b>	
No reported health problem	21
One reported health problem	39
Two reported health problem(s)	32
Three reported health problem(s)	8
Time period of onset of injury: 1961–1975/1976–1982 (%)	49/51

Abbreviations: AIS, ASIA Impairment Scale; ASIA, American Spinal Injury Association (International Neurological Standards for Classification of Spinal Cord Injury); s.d., standard deviation.

<sup>a</sup>Open question on currently perceived health problem.

**Table 2** Distribution of the subjects ( $n = 160$ ) into groups according to their self-reported main health problem

Main health problem	N (%)
No health problem	34 (21)
Pain	25 (16)
Urogenital problems	22 (14)
'My disability'	16 (10)
Musculoskeletal problems	16 (10)
<b>Other health concerns:</b>	
Bowel problems	10 (7)
Pressure ulcer(s)	7 (4)
Mental health	4 (3)
Autonomic dysreflexia	3 (2)
Spasticity	2 (1)
Other	21 (13)

Male subjects scored some higher with VT compared to female participants, but there were no significant gender differences. Concerning age (21 years or older versus younger than 21 years) at injury and time passed since injury (27 years or more versus less than 27 years), no differences were found between the groups. Persons with paraplegia scored significantly higher with PF compared to persons with

**Table 3** SF-36 multi-item scales in participants with SCI ( $N=160$ ) compared to Norwegian norm data ( $N=5152$ )

	Norm data (s.d.)	Adjusted norm data <sup>a</sup>	SCI (s.d.)	Deviation from adjusted norm	t <sup>b</sup>	Effect size <sup>b</sup>	P-value
Physical functioning	87.3 (19.4)	87.9	36.3 (26.0)	-51.7	-25.2	3.99	<0.001
Role Physical	77.7 (36.6)	78.9	74.1 (37.8)	-4.8	-1.6	0.26	0.11
Role Emotional	84.9 (31.0)	87.0	85.6 (31.0)	-1.4	-0.6	0.09	0.57
Bodily Pain	74.2 (25.5)	74.3	64.2 (27.1)	-10.0	-4.7	0.75	<0.001
Social Functioning	86.8 (20.6)	87.9	83.0 (26.0)	-4.9	-2.4	0.38	0.02
Mental Health	80.3 (15.4)	81.5	80.2 (15.8)	-1.3	-1.1	0.16	0.29
Vitality	60.9 (20.4)	63.4	59.3 (20.3)	-4.1	-2.6	0.41	0.01
General Health	75.5 (21.6)	75.6	69.4 (20.9)	-6.2	-3.8	0.60	<0.001

Abbreviation: s.d., standard deviation.

<sup>a</sup>Norm scores are adjusted to reflect age and gender distributions similar to those of the SCI participants.

<sup>b</sup>Calculated from *t*-values and d.f. in one sample *t*-test.

tetraplegia, however persons with tetraplegia exhibited higher HRQOL with RE. Persons with functionally complete SCI (AIS A–C) reported lower HRQOL with PF compared to persons with a less severe injury. Among persons currently employed, higher HRQOL were seen with the domains PF, RP, BP and SF compared to unemployed persons.

The reported 'no health problem' group scored significantly higher in six subscales compared with participants with health problem(s), and the ES was large for BP and medium for GH, RP, VT, SF and MH. Further, we observed higher scores with the subscales BP and GH for persons reporting one health problem only compared to individuals with more comorbid conditions/symptoms.

HRQOL was also analyzed for marital status and region of residence, but the scores did not show substantial differences between groups (data available on request).

## Discussion

The most important findings of this cross-sectional study were that persons with SCI of more than 20 years duration reported decreased HRQOL compared to the age- and gender-matched general population. The ES were moderate to large for physical components, and small to moderate for mental components. There were relatively small differences in the reported HRQOL according to the level and the extent of the SCI, as well as between genders within the study sample. The results also indicate that experiencing no comorbid conditions or symptoms and/or being currently employed are associated with a better HRQOL in persons with long-standing SCI.

The use of physical component summary (PCS) and mental component summary (MCS) scores have been discussed by other authors.<sup>7,18</sup> We decided not to use PCS/MCS, because in samples with particularly low PF scores, the MCS score will be highly inflated.<sup>7</sup> As an example, an Australian study<sup>8</sup> indicated better MCS scores in persons with SCI compared to norm data, and other studies described near-normal MCS scores in SCI populations. Haran *et al.*<sup>8</sup> listed four possible explanations of the high MCS scores including response shift, sampling bias and whether the study sample give a true reflection of the mental health of those with SCI. With regard to SCI research and the physical

health components of the SF-36, the authors also discussed the sensitivity of questions on physical functioning, which includes questions referring to walking.<sup>8</sup>

Price *et al.*<sup>21</sup> showed that a notable percentage of persons with SCI injured more than 20 years previously reported improvements in QOL. Westgren and Levi<sup>9</sup> suggested that individuals with SCI often develop adaptive strategies over time that allow them to cope with complications and deterioration in function. They concluded that HRQOL were better in persons injured many years ago compared to those more recently injured. Leduc and Lepage<sup>7</sup> did not find such a tendency in their study sample. We demonstrated that in persons with SCI of mean 27 years duration, the HRQOL is markedly low compared to norm data, and particularly with the physical health scales. However, our study showed higher scores in most subscales, and especially for physical role functioning, compared to other SCI populations, including reports on persons injured more than 20 years ago.<sup>6–11,22</sup> We have no exact explanation why the study group scored higher with SF-36 than shown by other authors, but hypothetically our results may be influenced by (1) generally high incomes and a high life standard in Norway; (2) the Norwegian welfare system that implies that costs of Health Service is free of charge, paid by the general Norwegian tax system; subsidized medication; the possibility of graded disability pensions and few economical disadvantages with working part-time compared with working full time; (3) adaptive strategies, as described above by Westgren and Levi. However, there is no comparable data on HRQOL in Norwegian persons with SCI of shorter duration to document improvements in HRQOL over time and (4) patient selection as described in section 'Limitations' below.

Not surprisingly, we found significant differences in HRQOL between persons reporting health problems versus those who did not. As seen in other studies,<sup>9</sup> experiencing health problems seems to have more negative effects on HRQOL than the level and extent of SCI as such. The findings underline that focus on prevention of medical complications and late consequences through systematic follow-up are still important issues after many years with SCI. Additionally, this study confirmed the results of prior studies demonstrating that being employed is related to better HRQOL.<sup>7,9</sup>

**Table 4** Comparison of HRQOL assessed with the Norwegian SF-36 between subgroups

Groups	n	Statistics	PF	RP	BP	GH	VT	SF	RE	MH
Male	132	Mean (s.d.)	38.2 (27.9)	74.4 (40.0)	65.0 (28.3)	69.7 (21.6)	60.5 (19.5)	82.2 (27.2)	87.1 (42.1)	80.3 (15.9)
Female	30	Mean (s.d.)	30.0 (20.9)	74.2 (37.4)	61.6 (24.0)	67.5 (18.5)	53.0 (22.8)	85.4 (21.8)	90.0 (24.9)	79.3 (14.8)
		<i>P</i>	0.752	0.974	0.546	0.609	0.065	0.546	0.720	0.752
		ES	0.29	0.005	0.12	0.10	0.38	0.11	0.07	0.06
Tetraplegic	54	Mean (s.d.)	22.5 (25.3)	76.3 (37.7)	68.1 (27.1)	60.0 (20.4)	58.0 (22.4)	80.0 (28.0)	99.4 (46.4)	79.9 (14.5)
Paraplegic	106	Mean (s.d.)	43.7 (25.0)	73.1 (40.3)	62.2 (27.5)	69.3 (21.1)	59.6 (19.1)	84.1 (25.3)	81.6 (34.0)	80.3 (16.4)
		<i>P</i>	<0.001	0.505	0.202	0.842	0.659	0.347	0.006	0.857
		ES	0.85	0.08	0.21	0.44	0.08	0.16	0.52	0.02
AIS A–C	136	Mean (s.d.)	30.9 (23.7)	75.3 (38.7)	63.7 (27.1)	69.6 (21.2)	60.3 (19.6)	81.5 (27.4)	87.5 (41.7)	80.8 (15.1)
AIS D–E	24	Mean (s.d.)	68.3 (23.8)	65.6 (43.4)	66.4 (29.3)	67.5 (18.8)	50.8 (22.2)	89.0 (18.5)	87.5 (25.6)	76.3 (19.6)
		<i>P</i>	<0.001	0.267	0.569	0.643	0.033	0.198	1.0	0.204
		ES	1.58	0.25	0.10	0.10	0.48	0.27	0.00	0.29
Employed	58	Mean (s.d.)	46.8 (29.6)	82.3 (37.4)	71.1 (23.3)	69.3 (19.0)	60.7 (19.3)	89.2 (16.2)	89.0 (26.0)	80.4 (14.4)
Not employed	104	Mean (s.d.)	30.7 (23.6)	69.6 (39.8)	60.4 (28.8)	69.6 (21.8)	58.1 (20.7)	79.0 (29.8)	86.8 (45.3)	80.0 (16.5)
		<i>P</i>	<0.001	0.05	0.017	0.947	0.426	0.018	0.732	0.90
		ES	0.68	0.32	0.37	0.01	0.13	0.34	0.05	0.02
Health problem(s)	126	Mean (s.d.)	35.9 (27.6)	67.6 (39.9)	59.4 (26.8)	65.9 (21.09)	55.8 (19.9)	79.6 (27.8)	86.2 (43.2)	78.0 (16.4)
No problem	34	Mean (s.d.)	39.1 (25.3)	97.0 (28.0)	82.7 (22.2)	82.2 (14.0)	70.4 (16.9)	93.7 (15.4)	92.1 (21.8)	87.8 (9.2)
		<i>P</i>	0.548	<0.001	<0.001	<0.001	<0.001	0.005	0.443	0.001
		ES	0.12	0.74	0.87	0.77	0.73	0.51	0.13	0.59
<i>Main problem:</i>										
Pain	25	Mean (s.d.)	35.4 (21.2)	59.0 (41.4)	34.2 (15.2)	69.3 (22.9)	50.4 (18.8)	68.5 (31.4)	65.3 (42.5)	74.1 (19.7)
Not pain	135	Mean (s.d.)	36.6 (27.9)	77.1 (38.4)	69.8 (25.5)	69.2 (20.7)	60.8 (20.1)	85.4 (24.3)	91.7 (37.5)	81.36 (14.6)
		<i>P</i>	0.830	0.033	<0.001	0.996	0.017	0.003	0.002	0.094
		ES	0.04	0.47	1.40	0.005	0.52	0.70	0.70	0.50
<i>Main problem:</i>										
Urogenital	22	Mean (s.d.)	46.1 (32.5)	79.5 (32.4)	67.0 (19.4)	61.7 (17.3)	58.4 (17.2)	89.2 (18.2)	93.9 (22.1)	83.5 (12.4)
Not urogenital	138	Mean (s.d.)	35.4 (26.3)	73.6 (40.3)	63.9 (28.5)	70.5 (21.3)	59.3 (20.7)	81.8 (27.2)	86.8 (41.4)	79.7 (16.2)
		<i>P</i>	0.983	0.509	0.629	0.07	0.843	0.22	0.428	0.306
		ES	0.41	0.15	0.11	0.41	0.04	0.27	0.17	0.23
One health problem <sup>a</sup>	63	Mean (s.d.)	37.1 (26.3)	70.6 (42.5)	68.7 (28.8)	72.7 (21.3)	60.1 (20.8)	84.5 (25.8)	87.3 (29.0)	81.0 (15.0)
Two or more	63	Mean (s.d.)	35.2 (27.1)	74.6 (36.9)	58.0 (25.9)	63.1 (19.6)	57.4 (19.7)	80.0 (27.7)	91.4 (50.5)	80.1 (13.7)
		<i>P</i>	0.704	0.582	0.032	0.01	0.464	0.350	0.578	0.736
		ES	0.07	0.09	0.37	0.45	0.13	0.17	0.14	0.06
<i>Age at injury</i>										
<21 years	78	Mean (s.d.)	37.8 (27.9)	76.9 (35.3)	67.7 (26.7)	69.7 (21.0)	59.5 (18.2)	82.1 (26.5)	93.2 (43.8)	80.6 (13.7)
≥21 years	84	Mean (s.d.)	35.3 (26.2)	72.1 (42.7)	61.3 (27.8)	68.9 (21.0)	58.9 (21.9)	83.5 (26.0)	82.7 (34.6)	79.9 (17.5)
		<i>P</i>	0.562	0.431	0.142	0.820	0.856	0.720	0.092	0.773
		ES	0.09	0.11	0.23	0.04	0.03	0.05	0.30	0.04
<i>Time since injury</i>										
<27 years	83	Mean (s.d.)	35.8 (27.5)	74.1 (40.9)	65.5 (26.9)	69.8 (21.7)	58.4 (21.7)	84.0 (24.1)	88.7 (47.2)	78.1 (17.4)
≥27 years	79	Mean (s.d.)	37.2 (26.5)	74.7 (37.8)	63.2 (28.0)	68.8 (20.3)	60.0 (18.6)	81.6 (28.3)	86.7 (29.3)	82.4 (13.7)
		<i>P</i>	0.741	0.923	0.609	0.760	0.624	0.550	0.736	0.08
		ES	0.05	0.01	0.08	0.04	0.07	0.10	0.04	0.25

Abbreviations: AIS, ASIA Impairment Scale; ASIA, American Spinal Injury Association (International Neurological Standards for Classification of Spinal Cord Injury); BP, Bodily Pain; ES, Effect Size; GH, General Health; MH, Mental Health; PF, Physical Functioning; RE, Role Emotional; RP, Role Physical; SF, Social Functioning; VT, Vitality.

<sup>a</sup>Only persons reporting one or more health problem(s) were included. Persons reporting no comorbid conditions or symptoms ( $n = 34$ ) were not included in this analysis.

### Limitations

First, we cannot conclude whether the participants were a representative group of Norwegian persons with SCI injured during the same period. Persons admitted to Sunnaas between 1961 and 1973 were possibly a more selected group than persons injured after 1973.<sup>23</sup> Second, we have little information concerning nonrespondents since the

Norwegian Directorate for Health and Social Affairs did not allow us to gather further details (gender, age, injury-etiology and so on.) without the patients' acceptance. Their response to a brief questionnaire added valuable information, but there is still lack of data concerning 23 out of the total sample of 237. It has been indicated that individuals with more severe conditions may be less likely to participate in

general population surveys, and this tendency might be seen in chronic conditions as well, including SCI populations. Therefore, the pattern of HRQOL in our total sample ( $n=237$ ) might show somewhat lower scores from the results presented, and the differences with the norm population are likely to be larger than the present findings. Further, long-term survivors might have had a better adjustment to their disability than persons who died early after injury. For this reason also, the results of HRQOL in persons with long-standing SCI might appear better than results of HRQOL measured at an earlier stage after injury. Third, these cross-sectional data reflect the respondents' situation at a certain point in time. Longitudinal studies may present a more accurate picture of HRQOL in SCI and make it possible to predict changes in HRQOL.

We registered health problems in a nonstandard way. Individuals also defined 'health problem' differently. As an example, 10% ( $n=16$ ) of the participants reported 'my disability' to be their main health problem. Many participants distinguished between their disabilities/impairments and 'health problem(s)' and did not define the disability itself as a health problem.

In conclusion, HRQOL is decreased in persons with long-standing SCI compared to norm data. There is potential for improvement of HRQOL even many years after the SCI. From the present results, we think that prevention of medical complications and long-term consequences are important factors to such improvement in persons with long-standing SCI. It is still important to focus on structured long-term follow-up in this population.

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