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Secondary health conditions, activity limitations and life satisfaction in older adults with long-term spinal cord injury

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Secondary health conditions, activity limitations and life satisfaction in older adults with long-term spinal cord injury

ABSTRACT

Background: Many individuals with a spinal cord injury (SCI) have lived several decades with their injury, leading to a need for a deeper understanding of factors associated with healthy aging in people with long-term SCI.

Objectives: To (1) describe secondary health conditions, activity limitations and life satisfaction in older adults with long-term SCI, and to (2) investigate how sociodemographics, injury characteristics and secondary health conditions are associated with their activity limitations and life satisfaction.

Design: Cross-sectional descriptive cohort study.

Setting: Home and community settings.

Participants: A total of 123 individuals (71% men, injury levels C1-L5, American Spinal Injury Association Impairment Scale A-D), mean age 63 years, mean time since injury 24 years.

Methods: Baseline data as part of the Swedish Aging with Spinal Cord Injury Study. Associations between variables were investigated with multivariable linear regression analyses.

Main outcome measurements: Bowel and bladder function, nociceptive and neuropathic pain, spasticity, the Spinal Cord Independence Measure, third version and the Satisfaction With Life Scale.

Results: Bowel-related and bladder-related problems were reported by 32% and 44%, respectively, 66% reported moderate or severe nociceptive and/or neuropathic pain, and 44% reported spasticity. Activity limitations were moderate (mean Spinal Cord Independence Measure, third version, total score 65.2, range 8-100) where injury characteristics and spasticity explained 68% of the variance. Higher level and more severe SCI (based on the American Spinal Injury Association Impairment Scale) exhibited the strongest association with more activity limitations. Life satisfaction was rated just above the midpoint between satisfied and dissatisfied with life (mean Satisfaction With Life Scale total score 20.7, range 6-34). Marital status, vocational situation, bladder function and injury characteristics explained 38% of the variance, where having a partner showed the strongest association with greater life satisfaction. Activity limitations and life satisfaction were not associated with gender, age and time since injury.

Conclusion: Older adults with long-term SCI can maintain a relatively high level of physical independence and generally are satisfied with their lives, regardless of gender, age or time

since injury. The associations demonstrate the importance of injury characteristics for the performance of daily activities and the social context for life satisfaction in older adults with long-term SCI.

KEY WORDS

Activities of daily living; Aging; Health Services for Persons with Disabilities; Rehabilitation; Spinal cord injuries

INTRODUCTION

As a result of advances in health care and rehabilitation, many individuals with spinal cord injury (SCI) have lived several decades after their injury [1]. In addition to the challenges of living with a neurologic disability, individuals with SCI are more susceptible to some age-related conditions [2] and experience earlier functional decline compared to the non-injured aging population [3]. Consequently, they are more likely to perceive decreased independence and superimposed activity limitations, which can negatively affect their well-being. This poses demands on society and health care to meet the needs of older adults with long-term SCI and support their healthy aging. Healthy aging can be defined as "the process of developing and maintaining the functional ability that enables well-being in older age" [4]. Hence, mitigating the consequences of a progressing disability would facilitate this process in older adults with long-term SCI. Although the life-long management of SCI has become a key physiatric area, and longitudinal studies have followed individuals with SCI for several decades [5-8], there is not yet a clear understanding of the consequences of aging with long-term SCI [2, 9]. In addition, most research on long-term SCI only includes individuals with a traumatic SCI (TSCI) and our knowledge of living with a non-traumatic SCI (NTSCI) is very limited.

Bowel and bladder dysfunction, pain and spasticity are considered the main secondary health conditions among individuals with SCI [10, 11], impeding on their activity and social participation [10], and thereby having a major impact on quality of life [12]. However, most SCI studies have not focused on older adults living with a long-term injury [11], and the association with sociodemographic factors, such as age and gender, and injury characteristics are not clear [9, 11]. The effects of age and duration of injury on functioning and disability have been studied both longitudinally and cross-sectionally [3, 13-15], but the results are inconclusive.

Because individuals with SCI now live longer there is an increasing need to ensure that aspects of their well-being are met [16]. One important area in SCI research is life satisfaction [17]. Life satisfaction commonly is referred to as an individual's subjective judgement upon the current life situation in relation to his or her own standards and expectations [18], and reflects the perception to which degree aspirations and achievements in life are being met. Life satisfaction seems to improve from a low level shortly after injury [16, 17] to a higher and stable level maintained over longer periods of time, although it still is lower than in the general population [17]. In studies of aging with SCI the results are,

however, inconsistent. Life satisfaction does not seem to be associated with severity of injury or degree of impairment [19] but with marital status, perceived health [20], time since injury and pain [16, 20]. These associations have mostly been studied in younger individuals (<50 years) [16] and our knowledge of life satisfaction in older adults with long-term SCI is therefore very limited.

Despite increased attention to aging with SCI during the past decades, there is still limited knowledge of living with long-term SCI into later life. Furthermore, as the result of cultural and contextual differences, it is challenging to relate existing findings across national contexts. To the best of our knowledge, there are no comprehensive data on older adults with long-term SCI from the perspective of Northern Europe, specifically the Nordic countries (approximately 27 million inhabitants).

To contribute to the knowledge of aging with SCI, the Swedish Aging with Spinal Cord Injury Study (SASCIS) [21] was initiated. The SASCIS is a population based, longitudinal cohort survey assessing individuals 50 years or older and at least ten years after a TSCI or NTSCI. In the first study, the methodology and initial results from the SASCIS are presented [21].

The objectives of the present study are to: (1) describe secondary health conditions, activity limitations and life satisfaction in older adults with long-term SCI, and (2) investigate how sociodemographics, injury characteristics and secondary health conditions are associated with their activity limitations and life satisfaction.

METHODS

The Swedish Aging with Spinal Cord Injury Study (SASCIS)

Detailed information about the SASCIS and the study design, recruitment process, ethical considerations, data collection procedure, participants and non-participants, assessment tools used and their psychometric properties, and data on the sociodemographics and injury characteristics of the study sample have been presented elsewhere [21].

Participants

In Sweden, with a population of about 10 million people, approximately 250 men and women (mean age 51 years) sustain a SCI annually [22]. Approximatly two thirds of the newly injured are 45 years or older and 54% have a TSCI. The total prevalence of TSCI in Sweden is estimated at about 5000 individuals [23]. The SCI Unit at Skåne University Hospital in

Lund, Sweden, from which all participants in the present study were recruited, serves a population of about 1.8 million people and admits about 50 persons with TSCI or NTSCI (mean age 51 years) each year for primary rehabilitation.

All participants were community-dwelling and recruited from the clinical databases at the SCI Unit. The databases comprise individuals with SCI who have been in contact with the unit during the past 40 years. The two main inclusion criteria were: 50 years of age or older and 10 years or more after TSCI or non-progressive, acquired NTSCI. A total of 184 individuals met the inclusion criteria; 123 individuals (36 women and 87 men, mean age 63, range 50-89, years) agreed to participate, giving a total response rate of 67% [21]. There were no significant differences between the non-participants and the study sample regarding gender, chronological age, age at injury, time since injury, SCI level (tetraplegia/paraplegia), injury severity (complete/incomplete) and cause of injury (TSCI/NTSCI) [21]. On the basis of this, we have concluded previously that our sample is likely to represent the population aging with long-term SCI in southern Sweden [21]. The severity of injury was classified according to the American Spinal Injury Association (ASIA) Impairment Scale (AIS) [24], based on the participants' medical records and confirmed during the data collection procedure (see below). For further comparisons between the participants, 3 groups of SCI severity were formed: (1) tetraplegia AIS A-C (*n*=22; 15 AIS A, 4 AIS B and 3 AIS C); (2) paraplegia AIS A-C (*n*=41; 23 AIS A, 8 AIS B and 10 AIS C); and (3) all AIS D (*n*=60).

Ethics

Before enrolment, each participant received information about the study and provided written informed consent to participate. The SASCIS was approved by the Regional Ethical Review Board in Lund, Sweden (No. 2010/692) and the Declaration of Helsinki for research on humans was followed.

Data collection procedure

Data were collected from the participants' medical records and by structured interviews and assessments during visits in their homes (*n*=122) or at another place (*n*=1). A study-specific questionnaire together with 4 SCI-specific and 8 generic assessment tools, all administered in Swedish, were used [21]. The assessment tools were chosen in order to cover the main parts

and components of the International Classification of Functioning, Disability and Health (ICF) [25]. For the present study a subset of the data was used to address the objectives.

Sociodemographics and injury characteristics

The following data on sociodemographic and injury characteristics were used in this study: gender, chronological age, marital status, vocational situation, age at injury, time since injury, cause of injury and level and severity of injury (represented by the 3 groups of SCI severity; see the section "Participants").

Secondary health conditions

Bowel and bladder function (voluntary versus nonvoluntary) and recurring bowel-related and bladder-related problems (ie, bowel and urinary incontinence, constipation, diarrhea, bowel irregularity, hemorrhoids, flatulence, urinary urgency and frequent urinary tract infections) during the past year were recorded (present versus not present), together with the occurrence of recurring neuropathic and/or nociceptive pain during the past year. The greatest intensity of nociceptive and neuropathic pain, respectively, experienced in daily life was rated with a standard Visual Analogue Scale for Pain (VAS-P; 0-100 mm between 'no pain' and 'the worst pain imaginable'). Mild pain was defined as 5-44 mm, moderate as 45-74 mm and severe pain as 75-100 mm [26]. For the analyses, we dichotomized pain into no or mild pain versus moderate or severe pain. The dichotomization was based on clinical judgement and previous research suggesting that only pain of moderate and high intensity interferes substantially with daily activities [27]. Spasticity was noted (present versus not present) if the participant reported spasticity that required treatment (eg, botulinum toxin, baclofen, gabapentin, diazepam) or reported untreated recurring spasticity during the past year.

Activity limitations

The Spinal Cord Independence Measure, third version (SCIM III) is a SCI-specific rating scale developed to assess the ability to perform daily activities [28]. The SCIM III comprises 19 tasks grouped into 3 subscales: self-care (score 0-20), respiration and sphincter management (score 0-40), and mobility (consisting of 2 subscales) (score 0-40) [28]. The total score ranges from 0 to 100 [28], where greater scores indicate less activity limitations. The SCIM III has been found psychometrically robust [21] and is suggested as the primary outcome measure of functional recovery after SCI [29].

Life satisfaction

The Satisfaction With Life Scale (SWLS) [30] is a generic measure of global life satisfaction that has been used extensively in various populations with life-long neurologic disabilities. It consists of 5 questions to be answered on a 7-point scale, ranging from 'strongly agree' to 'strongly disagree'. Item scores are summed, ranging from 5 to 35, where a greater score reflects greater life satisfaction and a score of 20 represents the mid-point between satisfied and dissatisfied with life. Scores were also stratified as: 'very high score; highly satisfied' (30-35 points), 'high score' (25-29 points), 'average score' (20-24 points), 'slightly below average in life satisfaction' (15-19 points), 'dissatisfied' (10-14 points) and 'extremely dissatisfied' (5-9 points) [31]. The SWLS has demonstrated good reliability and validity [21] and normative data are available [32].

Data and statistical analysis

Descriptive statistics were computed for all variables. Between-group differences for the different variables were analyzed using the Kruskal-Wallis test, the Mann-Whitney U-test or the Chi-square test, as appropriate. The Spearman rank correlation coefficient was used to analyze bivariate associations between variables. As the study is of descriptive character, no adjustment for multiple tests was performed [33].

To investigate factors associated with activity limitations and life satisfaction, multivariable linear regression analyses were performed. Independent variables were chosen on the basis of the objectives of the study, previous research and clinical judgement. In the first step, associations between the dependent variables (SCIM III total score and SWLS total score) and possible independent variables were investigated by means of univariable linear regression analyses. As the level and severity of injury were represented by the 3 groups of SCI severity, dummy variables for tetraplegia AIS A-C and paraplegia AIS A-C, with the all AIS D as the reference category, were created.

For the model with SCIM III as the dependent variable, the independent variables were: gender, age, level and severity of injury, time since injury, cause of injury, nociceptive and neuropathic pain and spasticity. Bowel and bladder function and related problems were not included as independent variables as items in the SCIM III cover them. For the model with SWLS as the dependent variable, the independent variables were: gender, age, marital status, vocational situation, level and severity of injury, time since injury, cause of

injury, bowel and bladder function and related problems, nociceptive and neuropathic pain, and spasticity. Independent variables were then included in the multivariable analyses if the p-value was less than .30.

For activity limitations, the multivariable linear regression analysis was performed with the total SCIM III score as the dependent variable. The independent variables were level and severity of injury, time since injury (in 10 year intervals), cause of injury and spasticity. The model exhibited no multicollinearity, the residuals were normally distributed, and there was no deviation from linearity and no heteroscedasticity.

For life satisfaction, the multivariable linear regression analysis was performed with the SWLS total score as the dependent variable. The independent variables were paraplegia AIS A-C, cause of injury, marital status, vocational situation, bowel and bladder function and related problems and neuropathic pain. Because of the strong associations between activity limitations and level and severity of injury, it was not possible to include the SCIM III total score in the regression model. As the focus throughout the study was to compare the 3 groups of SCI severity, it was considered more appropriate to exclude activity limitations (ie, SCIM III) from the model. The model exhibited no multicollinearity and no heteroscedasticity, and the residuals were normally distributed.

All statistical analyses were performed using the SPSS v. 22 software for Windows (IBM Corporation, Armonk, New York, United States). P-values less than .05 represent statistical significance.

RESULTS

Sociodemographics and injury characteristics

Data on sociodemographics and injury characteristics for the total sample and the 3 groups of SCI severity are presented in Table 1. Men and women did not differ significantly regarding chronological age, marital status, vocational situation, age at injury or time since injury. The all AIS D included more women than the paraplegia AIS A-C (p=.04). The 3 groups of SCI severity did not differ significantly regarding chronological age, marital status or vocational situation. Compared to the tetraplegia AIS A-C and the paraplegia AIS A-C, respectively, the all AIS D were more likely to have a NTSCI (p=.001; p<.001), were older at injury (p=.001; p=.01), and had a shorter time since injury (p<.001; p=.001).

Insert Table 1 about here

Secondary health conditions

Almost half of the participants reported voluntary bowel function without using laxatives and 68% did not report any bowel-related problems (Table 2). Bowel function was related to group of SCI severity ($p \leq .006$); pair-wise comparisons between the 3 groups of SCI severity revealed that participants in the all AIS D were most likely and those in the tetraplegia AIS A-C least likely to have voluntary bowel function. Participants with TSCI were less likely to have voluntary bowel function ($p=.02$) than those with NTSCI. There were no significant differences between participants with voluntary and nonvoluntary bowel function regarding gender, chronological age, age at injury and time since injury.

Fifty-three participants (43%) used clean intermittent catheterization (CIC) and 56% did not report any bladder-related problems (Table 2). Use of indwelling catheters was most common in the tetraplegia AIS A-C. Participants in the all AIS D were more likely to have voluntary voiding compared to those in the tetraplegia AIS A-C ($p<.001$) and paraplegia AIS A-C ($p<.001$), but there was no significant difference between the latter 2 groups. Participants with TSCI were less likely to have voluntary voiding ($p=.007$) than those with NTSCI. Participants with voluntary voiding were older at injury ($p<.001$) and had a shorter time since injury ($p<.001$), with no relation to gender or chronological age.

There were no significant differences between participants with and without bowel-related or bladder-related problems regarding gender, chronological age, age at injury, time since injury, cause of injury and level and severity of injury.

Insert Table 2 about here

A large majority (*n*=105; 85%) reported some form of pain and 42% reported both nociceptive and neuropathic pain (Table 3). Sixty-six percent reported moderate or severe nociceptive and/or neuropathic pain. Participants who reported moderate or severe neuropathic pain were older at injury ($p=.02$), had a shorter time since injury ($p=.03$) and were less likely to be vocationally active ($p=.004$) compared to those reporting no or mild neuropathic pain. No such differences were found regarding nociceptive pain. There were no significant differences between participants reporting no or mild pain compared with those reporting moderate or severe pain regarding gender, chronological age, cause of injury and level and severity of injury.

Spasticity was present in 54 participants (44%). There were no significant differences between participants with and without spasticity regarding gender, chronological age, cause of injury, level and severity of injury, age at injury and time since injury.

Insert Table 3 about here

Activity limitations

The range of the total SCIM III score varied considerably with a mean of 65.2 (range 8 to 100) (Table 4). There was no significant difference in the total SCIM III score between the men and the women. Activity limitations were related to group of SCI severity ($p<.001$); pair-wise comparisons between the 3 groups revealed that participants in the tetraplegia AIS A-C had the most activity limitations and those in the all AIS D the least. Participants with a TSCI had more activity limitations than those with a NTSCI ($p<.001$). Activity limitations were weakly, but significantly, correlated with age at injury (rho=.280; $p=.002$) and time since injury (rho=-.373; $p<.001$), indicating more activity limitations in those injured at younger ages and with longer time since injury. There was no significant relationship with chronological age and no significant difference among participants reporting no or mild pain compared with those reporting moderate or severe pain. Participants with spasticity had significantly more activity limitations ($p=.003$).

Insert Table 4 about here

In the multivariable linear regression analysis the independent variables explained 68% of the variance in activity limitations (Table 5). Higher level and more severe SCI (based on the AIS) together with spasticity were significantly associated with more activity limitations, with the level and severity of injury being the strongest contributor to the model.

Insert Table 5 about here

Life satisfaction

The mean SWLS total score was 20.7 (Table 6), which is just above the midpoint (score 20) between satisfied and dissatisfied with life. Thirty-seven participants (33%) had a total score

of 25 or more, indicating that they were satisfied (n=23) or highly satisfied (n=14) with life. Twenty-four participants (22%) reported an average score (20-24), whereas 28 participants (25%) had a total score 14 or less, indicating that they were dissatisfied (n=23) or extremely dissatisfied (n=5) with life. There were no significant differences between men and women, participants with TSCI and NTSCI or between the 3 groups of SCI severity. Participants who had a partner and/or were working full-time or part-time rated their life satisfaction significantly greater ($p<.001$), as did those reporting voluntary bowel function ($p=.04$) and/or voluntary voiding ($p=.03$). There was no significant difference in life satisfaction among participants reporting no or mild pain compared with those reporting moderate or severe pain. Similarly, there was no significant difference between participants with spasticity and/or bladder-related or bowel-related problems compared with participants who did not report these problems. There was no significant association between activity limitations (total SCIM III score) and life satisfaction (total SWLS score).

Insert Table 6 about here

In the multivariable linear regression analysis, the independent variables explained 38% of the variance in life satisfaction (Table 7). Paraplegia AIS A-C, having a partner, working full-time or part-time and voluntary voiding were all significantly associated with a high life satisfaction, with marital status being the strongest contributor to the model.

Insert Table 7 about here

DISCUSSION

To the best of our knowledge, this is the first study describing secondary health conditions, activity limitations and life satisfaction in older adults with long-term SCI from the perspective of Northern Europe, specifically the Nordic countries. The main findings were that 32% and 44% of the participants, respectively, reported bowel-related and bladder-related problems, 66% reported moderate or severe nociceptive and/or neuropathic pain, and 44% reported spasticity. Second, activity limitations were on average moderate, with injury characteristics and spasticity explaining about two thirds of the variance. Third, life satisfaction was rated just above the midpoint between satisfied and dissatisfied with life, with marital status, vocational situation, bladder function and injury characteristics explaining over

a third of the variance. Finally, gender, age and time since injury were not associated with the participants' activity limitations and life satisfaction.

Secondary health conditions

Neurogenic bowel and bladder dysfunction, pain and spasticity are frequently reported secondary health conditions after SCI [10, 11]. The occurrence of bowel-related (32%) and bladder-related (44%) problems in the present study is lower compared with that from the Netherlands (*n*=454, mean age 48 years, mean time since injury 13 years) [10], where bowel-related problems were described by 61% and bladder-related problems by 71%. That study [10] consisted of more individuals with complete SCI who might experience more bowel-related and bladder-related problems; however, we did not find any associations between these problems and the level and severity of injury. CIC was the most common bladder evacuation method, and suprapubic catheters were mostly used in the tetraplegia AIS A-C, which is in agreement with findings from other European studies of people with SCI of different ages [34-36].

Data on pain in the SCI population vary greatly. In the present study, gender, cause of injury and level and severity of injury were not associated with the occurrence of pain, which is in line with previous reports [37, 38]. The occurrence of neuropathic pain among our participants (66%) is higher compared to previous Swedish studies where 32%-40% reported neuropathic pain [39, 40]. This finding may be explained by an older age at injury in our sample. The finding that neuropathic pain was more common in individuals injured at older ages is in agreement with previous studies [38, 40]. Furthermore, our sample consisted of more individuals with incomplete injuries who could experience pain as more disabling than their neurologic sequelae. Pain has been reported to be more frequent in individuals with AIS D injuries [41], but we found no associations between the level and severity of injury and pain. Taken together, pain seems to be common in older adults with long-term SCI, which should be considered in clinical practice and future research. To allow for a greater understanding of pain, more in-depth descriptions are warranted. Accordingly, ratings of average pain intensity, the experience of allodynia and the effect of analgesics should be considered.

The occurrence of spasticity in our sample (44%) is lower compared with previous studies of people with chronic SCI, where 53%-78% had spasticity [42, 43]. Individuals with lower level injuries and incomplete cervical injuries are less prone to develop

spasticity [42, 44]. Our sample included only 15 individuals with complete cervical injuries and the most common type of injury was incomplete paraplegia [21], which most likely explains the differences with previous studies.

Activity limitations

The SCIM III score indicated a large difference in activity limitations among the participants, but in general a relatively high level of independence and only moderate overall activity limitations. The finding that the level and severity of injury were strongly associated with activity limitations is supported by results from other studies in which the SCIM III [45] or the Functional Independence Measure (FIM) [46, 47] was used. In studies of individuals with chronic TSCI and NTSCI, higher chronological age seems to negatively affect functional ability [14, 48]. Our study did not reveal any associations between activity limitations and older age. Some of these discrepancies could be the result of differences in study design, in particular the age range of the included participants. In the multivariable analysis, spasticity was significantly associated with more activity limitations, although less strongly than the level and severity of injury. Nevertheless, our results indicate that spasticity can interfere with the performance of ADL, which is supported by clinical experience as well as earlier research [10, 42, 44].

Although pain has been reported to interfere with daily life and social activities in individuals with SCI [10], we did not find any significant associations between pain and activity limitations. One plausible explanation could be that among individuals with long-term SCI, pain is present but it is no longer taking precedence in daily life. Thus, our results imply that the level and severity of injury is one main factor associated with activity limitations, regardless of chronological age and time since injury.

Life satisfaction

There was a large variability in life satisfaction among the participants, from highly dissatisfied to highly satisfied, with a mean SWLS total score of 20.7. According to Diener [31], this score indicates that older adults with long-term SCI can be considered generally satisfied although there are some areas where they very much would like some improvement. The ratings of life satisfaction in our sample are comparable to findings in Swedish studies of individuals with traumatic brain injury [49] and Parkinson's disease [50], although lower than a nationwide sample of Swedish university students (n=2900) [32]. Life satisfaction among

our participants also was similar to ratings found in individuals with acute SCI (SWLS total score 20.4) [51] and chronic SCI (SWLS total score 20.8) [52] of both traumatic and non-traumatic etiology. DeVivo and Chen [53] examined life satisfaction in individuals 1-30 years post-TSCI and found the greatest ratings of life satisfaction in those with the longest duration of injury (SWLS total score 22.5). Thus, life satisfaction seems to remain relatively stable a long time after SCI, and may in fact increase as one lives longer with the injury. This could perhaps be attributed to follow-up bias, as people who are less satisfied with life tend to withdraw from research projects [19]. Nevertheless, Charlifue et al [20] reported that with increasing time since injury, life satisfaction seems to improve despite a decline in perceived health status.

The independent variables explained as much as 38% of the variance in life satisfaction, which is comparable to previous reports [20, 52]. This indicates that other factors may also be associated with life satisfaction among older adults who have lived with a SCI for many years. Previous research has suggested significant associations with psychological distress and depression [52], sense of coherence [17], perceived health status [52] and community participation [52, 54] in individuals with SCI. Furthermore, engagement in physical activity has demonstrated positive effects on life satisfaction [55]. As there is very limited knowledge about such associations in older adults with long-term SCI, these are important areas for future research.

Our finding that pain was not associated with life satisfaction is somewhat surprising, as this has been found in previous studies [52, 56, 57]. However, the lower ratings of life satisfaction in individuals with pain might be mediated by negative mood states [56], even though the directional causality between these variables is not fully known [57]. Our results also show that pain is associated with vocational situation, which, in turn, is significantly associated with life satisfaction. Thus, pain covaries with many aspects of life that may be related to life satisfaction, which could explain why no such direct association was found in the present study. In order to study mediators of such complex dynamics, further research using alternative approaches is warranted.

As expected, participants who had a partner rated a greater life satisfaction. This is well in line with previous research, both in people with SCI and noninjured populations [58-61]. There are plausible explanations to why this association is so commonly described. Having a partner is a source of social, physical, emotional and financial support [59], and provides a sense of belonging and being needed. Moreover, life satisfaction reflects the degree

to which achievements and aspirations in life are met, and having a relationship and founding a family is important for many people. Life satisfaction among our participants was also associated with vocational status, which indicates the importance of meaningful and productive daily activities. This association has previously been described in individuals with SCI [60] as well as in the general population [62]. Thirty-five percent of our participants were vocationally active. Whether life satisfaction in this group diminishes as they retire presents an interesting topic for future studies.

Thus, the established association between life satisfaction and the social environment holds true also for older individuals with long-term SCI. Forthcoming longitudinal studies in our cohort will further enhance our knowledge of life satisfaction in older adults many years after SCI.

Strengths and limitations

Several strengths of the SASCIS have been previously discussed [21]. There are also a few limitations to the present study. Pain was rated as the highest pain intensity experienced in everyday life, which could have led to an overestimation of pain intensity and we might also have failed to recognize participants that were truly restricted by severe pain. Consequently, the lack of an association between pain, activity limitations and life satisfaction should be interpreted with some caution. Spasticity was based on self-reports and not physically examined which should be kept in mind when interpreting the results. The SCIM III was scored by interview and not by observation, which could have affected the scoring precision. Because of the cross-sectional study design, we were unable to identify factors predicting activity limitations and life satisfaction, and could only show associations between the investigated variables. Studies with data from several time points are therefore needed to understand factors that predict disability. Hence, forthcoming longitudinal studies from the SASCIS will contribute to a more comprehensive understanding of aging with long-term SCI.

Conclusion

Older adults with long-term SCI in southern Sweden can maintain a relatively high level of physical independence and generally are satisfied with their lives, regardless of gender, age or time since injury. Pain is common but does not seem to be associated with activity limitations and life satisfaction. The associations between variables demonstrate the importance of injury characteristics for the performance of daily activities and the social context for life

satisfaction in older adults with long-term SCI. In physiatric practice, maintaining a low frequency of secondary health conditions, and facilitating meaningful activities and social interaction therefore seem to be important for healthy aging many years after SCI.

Taken together, this study indicates that older adults with long-term SCI in southern Sweden exhibit both differences and similarities compared to other SCI populations. Future studies from the SASCIS will add to the overall knowledge base of living with long-term SCI into later life and contribute to our understanding of factors that promote healthy aging in this segment of the population.

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Table 1. Sociodemographics and injury characteristics of older adults with long-term spinal cord injury (*n* = 123)

	Total (*n* = 123)	Tetraplegia AIS A-C (*n* = 22)	Paraplegia AIS A-C (*n* = 41)	All AIS D (*n* = 60)
Gender[1a] (*n* (%))				
Men	87 (71)	15 (68)	34 (83)	38 (63)
Women	36 (29)	7 (32)	7 (17)	22 (37)
Age, y, mean ± SD; median, range	63 ±9; 63, 50-89	60 ±7; 59, 50-77	63 ±9; 61, 50-78	65 ±9; 64, 50-89
Age at injury, y, mean ± SD; median, range[1b,2a]	39 ±16; 38, 7-74	31 ±13; 29, 17-62	36 ±15; 32, 7-63	45 ±16; 49, 12-74
Time since injury, y, mean ± SD; median, range [1c,2b]	24 ±12; 22, 10-56	30 ±9; 29, 13-48	27 ±12; 27, 10-56	20 ±11; 15, 10-50
Cause of injury, *n* (%)[1d,2c]				
Traumatic[3]	76 (62)	18 (82)	34 (83)	24 (40)
Non-traumatic[4]	47 (38)	4 (18)	7 (17)	36 (60)
Marital status *n* (%)[5]	65 (53)	13 (59)	24 (59)	28 (47)
Vocational situation, *n* (%)				
Working full-time or part-time	43 (35)	8 (36)	15 (37)	20 (33)
Disability pension	34 (28)	8 (36)	12 (29)	14 (23)
Old age pension	46 (37)	6 (27)	14 (34)	26 (43)

AIS = American Spinal Injury Association Impairment Scale [24]; SD = standard deviation.

[1]Significant differences between the paraplegia AIS A-C and the all AIS D. [a] p=.04; [b] p=.01; [c]p=.001; [d]p<.001

[2]Significant differences between the tetraplegia AIS A-C and the all AIS D. [a] p=.001; [b]p<.001; [c]p=.001

[3]Traffic/transportation (motor vehicle, train, bicycle), fall, workplace accident, diving accident, gunshot/assault/torture, other traumatic (eg, sports, leisure activities).

[4]Spinal tumour, spinal disk herniation, spinal arteriovenous malformation, spinal infarction, spinal infection.

[5]Having a partner/married/co-habiting.

Table 2. Bowel and bladder function, and related problems among older adults with long-term spinal cord injury (*n* = 123)

Bowel function, *n* (%)[1,2]	
Voluntary bowel function	58 (47)
Nonvoluntary bowel function[3]	65 (53)
Bowel-related problems, *n* (%)[1,4]	39 (32)
Incontinence	15 (12)
Constipation	14 (11)
Other[5]	19 (15)
Bladder function, *n* (%)[1,6]	
Voluntary voiding	46 (37)
Voluntary voiding and CIC	6 (5)
Nonvoluntary voiding	77 (63)
CIC	47 (38)
Indwelling catheter	21 (17)
Foley catheter	6 (5)
Suprapubic catheter	15 (12)
Other[7]	11 (9)
Bladder-related problems, *n* (%)[1,4]	54 (44)
Incontinence	32 (26)
Urgency	17 (14)
Frequent urinary tract infections (UTIs)[8]	12 (10)
Other[9]	5 (4)

CIC = clean intermittent catheterization; AIS = American Spinal Injury Association Impairment Scale [24]

[1]Several participants reported more than 1 type of bowel/bladder function and related problems.

[2]Higher frequency of voluntary bowel function among the all AIS D (n=60) compared with the tetraplegia AIS A-C (n=22), p<.001, and the paraplegia AIS A-C (n=41), p=.001, and among the paraplegia AIS A-C compared with the tetraplegia AIS A-C, p=.006.

[3]Use of laxatives, digital stimulation, colostomy.

[4]Defined as recurring bowel-related or bladder-related problems during the past year.

[5]Eg, diarrhea, irregularity, hemorrhoids, flatulence.

[6]Greater frequency of voluntary voiding among the all AIS D compared with the tetraplegia AIS A-C, p<.001, and the paraplegia AIS A-C, p<.001.

[7]Eg, urostomy, bladder reflex triggering, bladder expression.

[8]Defined as recurring UTIs more than 3 times/y.

[9]Eg, time-consuming, bladder stones.

Table 3. Pain and spasticity among older adults with long-term spinal cord injury (*n* = 123)

No pain, *n* (%)	18 (15)
Nociceptive pain, *n* (%)[1]	76 (62)
Mild (VAS 5-44)	27 (22)
Moderate (VAS 45-74)	30 (24)
Severe (VAS 75-100)	19 (15)
VAS-P in mm, mean ± SD; range	34 ±33; 0-100
Neuropathic pain, *n* (%)[1,2]	81 (66)
Mild (VAS 5-44)	16 (13)
Moderate (VAS 45-74)	28 (23)
Severe (VAS 75-100)	33 (27)
VAS-P in mm, mean ± SD; range	42 ±37; 0-100
Both types of pain, *n* (%)	52 (42)
Spasticity, *n* (%)[3]	54 (44)

VAS = Visual Analogue Scale for pain (VAS-P; 0-100 mm); AIS = American Spinal Injury Association Impairment Scale [24]

[1]Defined as recurring pain during the past year. Pain intensity was classified according to Jensen et al. [26]

[2]One participant reported occurrence of neuropathic pain but was unable to rate the intensity, 1 participant reported occurrence of neuropathic pain but rated the intensity to 4 mm and 2 participants reported occurrence of neuropathic pain but rated the intensity as 0 with analgesics.

[3]Defined as spasticity requiring treatment or untreated, recurring spasticity during the past year.

Table 4. Activity limitations among older adults with long-term spinal cord injury (*n* = 123) as assessed with the SCIM III

	SCIM total score[1]
Total sample (*n* = 123)	65.2 ±24.2; 8-100
Tetraplegia AIS A-C (*n* = 22)	27.9 ±13.1; 8-66
Paraplegia AIS A-C (*n* = 41)	62.0 ±13.0; 31-85
All AIS D (*n* = 60)	81.1 ±15.8; 31-100

Data are presented as mean ± standard deviation; range.
The SCIM III [28] comprises 19 tasks grouped into 3 subscales: self-care (score 0-20), respiration and sphincter management (score 0-40), and mobility (consisting of 2 subscales) (score 0-40). The total score ranges from 0 to 100, where greater scores indicate less activity limitations.
SCIM III = Spinal Cord Independence Measure, third version; AIS = American Spinal Injury Association Impairment Scale [24]
[1]Significant differences between the 3 groups of SCI severity (all pairwise comparisons yielded p-values <.001).

Table 5. Multivariable linear regression with the SCIM III total score as the dependent variable among older adults with long-term spinal cord injury (*n* = 123)

Independent variables[1]	Unstandardized regression coefficient B	95 % confidence interval for B	p-value
Tetraplegia AIS A-C[2]	-49.3	(-56.7, -41.8)	<.001[3]
Paraplegia AIS A-C[2]	-17.4	(-23.5, -11.2)	<.001[3]
Time since injury (in 10 year intervals)	-1.3	(-3.6, 1.1)	.28
Non-traumatic injury	2.5	(-3.4, 8.3)	.41
Spasticity	-9.5	(-14.5, -4.4)	<.001[3]
Adjusted R^2		0.68	

Greater SCIM III total score indicate less overall activity limitations (range 0-100).
SCIM III = Spinal Cord Independence Measure, third version; AIS = American Spinal Injury Association Impairment Scale [24]
[1]Independent variables with p<.30 in univariable regression analyses with the SCIM III total score as the dependent variable.
[2]Reference category: All AIS D.
[3]Denotes p-values that are statistically significant (p<.05)

Table 6. Life satisfaction among older adults with long-term spinal cord injury (*n* = 111) as assessed with the Satisfaction With Life Scale (SWLS).

	SWLS total score
Total sample (*n* = 111)	20.7 ±7.1; 6-34
Tetraplegia AIS A-C (*n* = 19)	20.4 ±7.3; 10-34
Paraplegia AIS A-C (*n* = 36)	21.9 ±7.9; 6-33
All AIS D (*n* = 56)	20.0 ±6.6; 6-34

Data are presented as mean ±standard deviation; range.
The SWLS [30] consists of 5 questions to be answered on a seven-point scale, ranging from 'strongly agree' to 'strongly disagree'. Item scores are summed, ranging from 5 to 35, where a greater score reflects greater life satisfaction and a score of 20 represents the mid-point between satisfied and dissatisfied with life.
SWLS = Satisfaction With Life Scale; AIS = American Spinal Injury Association Impairment Scale [24].

Table 7. Multivariable linear regression with the SWLS total score as the dependent variable among older adults with long-term spinal cord injury (*n* =111)

Independent variables[1]	Unstandardized regression coefficient B	95 % confidence interval for B	p-value
Paraplegia AIS A-C[2]	3.4	(0.8, 6.1)	.01[3]
Nontraumatic injury	2.1	(-0.4, 4.6)	.10
Having a partner	6.0	(3.8, 8.2)	<.001[3]
Working full-time or part-time	3.9	(1.5, 6.3)	.002[3]
Nonvoluntary bowel function	-0.3	(-3.0, 2.4)	.82
Bowel-related[4] problems	0.6	(-2.0, 3.3)	.63
Nonvoluntary voiding	-4.2	(-7.0, -1.4)	.004[3]
Bladder-related[5] problems	-2.3	(-4.7, 0.03)	.05
Moderate or severe neuropathic pain[6]	-1.2	(-3.5, 1.1)	.30
Adjusted R^2		0.38	

Greater scores indicate greater life satisfaction (range 5-35).
SWLS = Satisfaction With Life Scale; AIS = American Spinal Injury Association Impairment Scale [24].
[1]Independent variables with p<.30 in univariable regression analyses with the SWLS total score as the dependent variable.
[2]Reference category: Tetraplegia AIS A-C and all AIS D.
[3]Denotes p-values that are statistically significant (p<.05)
[4]Reference category: No bowel-related problems.
[5]Reference category: No bladder-related problems.
[6]Reference category: No or mild neuropathic pain.