Research Article Global and domain-specific life satisfaction among older adults with long-term spinal cord injury

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Objective: Although life expectancy after spinal cord injury (SCI) has increased, knowledge of life satisfaction and associated factors among older adults with long-term SCI is still very limited. The objective of this study was, therefore, to assess global and domain-specific life satisfaction among older adults with long-term SCI and investigate the association with sociodemographics, injury characteristics and secondary health conditions. Design: Cross-sectional cohort study. Data from the Swedish Aging with Spinal Cord Injury Study (SASCIS). Setting: Community settings in southern Sweden.

Participants: Seventy-eight individuals (32% women, injury levels C1-L3, American Spinal Injury Association Impairment Scale (AIS) A-D) mean age 68 years, mean time since injury 31 years. Interventions: Not applicable.

Outcome measures: The Life Satisfaction Questionnaire (LiSat-11).

Results: The participants were at least rather satisfied with most of the 11 life domains. They rated the lowest satisfaction with sexual life, activities of daily living and somatic health. Having a partner and being vocationally active was associated with greater satisfaction with life as a whole and with several other life domains. Participants with AIS D injuries were less satisfied with their somatic health than those with tetraplegia AIS A-C and paraplegia AIS A-C injuries. More secondary health conditions were negatively associated with satisfaction in five life domains.

Conclusion: Life satisfaction can be affected many years after SCI. The social context, participation in meaningful activities and minimizing secondary health conditions seem to be important for maintaining life satisfaction in older adults with a long-term injury.

Keywords: Aging, Quality of life, Rehabilitation, Spinal cord injuries

Introduction

As many individuals with spinal cord injury (SCI) today are expected to live long lives, it is essential that all aspects of their well-being are met. One important area in this regard is life satisfaction. Life satisfaction refers to a subjective judgement upon the current life situation in relation to a person's own standards and expectations,¹ and includes an evaluation of the extent to which life goals have been

achieved.² Satisfaction with life is often low initially after SCI but generally improves to a higher and stable level as an individual adapts to the consequences of the injury.³ Nevertheless, life satisfaction among persons with SCI still remains lower than in the non-injured population.⁴ As life satisfaction is closely associated with the adaptation process after injury, it can be regarded as an overarching goal of SCI-rehabilitation.

Life satisfaction is important to consider in older ages given the association with health and longevity.⁵ Studies including older adults from the general population have

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shown that life satisfaction can increase with age,^{5,6} and that poorer self-perceived health,⁶ more physical impairments⁷ and living alone/being unmarried are associated with lower levels of life satisfaction.⁸

Contrary to common beliefs, life satisfaction does not seem to be associated with the level and severity of SCI, but instead with employment, marital status, perceived health, time since injury and secondary health conditions (SHCs), such as pain and bowel-related problems.9-12 Previous studies regarding life satisfaction and SCI have predominantly included younger people with a wide range of years after injury^{3,10} and there are very few studies of life satisfaction in older adults with long-term SCI. Post and Reinhart¹³ studied life satisfaction and participation in 128 persons with SCI who were all at least 65 years old and investigated differences in relation to age at injury (above or below 50 years of age). This study¹³ included older adults with both long-term and short-term injury and showed that longer time since injury was associated with greater life satisfaction. In addition, Krause et al.¹⁴ studied changes in life satisfaction among 49 individuals at least 40 years after SCI and mean age of 65 years. They found that satisfaction with social life, sex life and general health increased until 11 years after the injury, and then decreased. These studies contribute to our understanding of life satisfaction in older adults with long-term SCI. However, further studies are needed to expand our knowledge in this area, in particular from a Northern European perspective.

We have previously reported on satisfaction with life as a whole in a population of older adults with longterm SCI in Sweden.¹⁵ In this study, having a partner and being vocationally active were the strongest explanatory factors for a high level of life satisfaction.¹⁵ However, to the best of our knowledge, no study has assessed satisfaction with different life domains and associated factors in this specific population. Studying domain-specific life satisfaction may give an indication of how society supports and provides healthcare and rehabilitation for these individuals. Knowledge of factors associated with satisfaction with different life domains among older adults with long-term SCI can be used to design rehabilitation programs and interventions tailored to their specific needs and thereby improve long-term management after injury.

The aims of this study are to describe satisfaction with life as a whole and with different life domains among older adults with long-term SCI and to investigate associations between life satisfaction and sociodemographics, injury characteristics and SHCs (bowelrelated and bladder-related problems, spasticity and nociceptive and neuropathic pain). We hypothesize that satisfaction with life domains related to physical functioning are affected in older adults with long-term SCI and that sociodemographics exhibit a stronger association with life satisfaction than injury characteristics and SHCs.

Methods

Research design

This study is part of the Swedish Aging with Spinal Cord Injury Study (SASCIS), a population-based, longitudinal cohort study assessing individuals 50 years or older and at least 10 years after SCI.¹⁶ The overarching aim of the SASCIS is to contribute to our knowledge of factors associated with healthy aging in persons with long-term SCI. Data were collected at interviews and assessments in the participants' homes. The initial data collection of the SASCIS was finalized in 2012 and this study is based on a follow-up, cross-sectional data collection conducted in 2017 and 2018. The SASCIS is informed by the STROBE (Strengthening the reporting of observational studies in epidemiology) statement for cohort studies.¹⁷

Participants

The participants were recruited through databases at the SCI Unit at Skåne University Hospital in Lund, Sweden and were all living in the community. This SCI Unit serves a catchment area of 1.9 million people and is responsible for primary rehabilitation of individuals with newly acquired SCI in southern Sweden. The main inclusion criteria of the SASCIS were: (i) at least 50 years of age and (ii) at least 10 years after traumatic SCI or acquired, non-progressive non-traumatic SCI. The participants were also required to understand written and oral information in Swedish and reside in the southern part of Sweden.

When the initial data collection was conducted (years 2011–2012), the SASCIS cohort included 123 participants. When the follow-up data collection was initiated in 2017, 101 persons from the original cohort were still alive. Twenty-three persons declined to participate in the follow-up and the final study sample comprised 78 (32% women) of the original study participants. Their mean age was 68 years and their mean time since injury was 31 years. Based on the ASIA Impairment Scale (AIS),¹⁸ three different groups of SCI level and severity were formed: i) tetraplegia AIS A-C (n = 12), (ii) paraplegia AIS A-C (n = 26) and (iii) all AIS D (n = 40).¹⁹

When comparing the current sample (78 participants) with the drop-outs (n = 23), the only significant

differences were found regarding time since injury and age at injury; the participants were younger at injury (P = 0.021) and had lived a longer time with their injury (P < 0.001) than the non-participants.

Ethics

All participants were given written and oral information about the study before enrollment and provided their written informed consent to participate. The principles of the Declaration of Helsinki for research on humans were followed throughout the course of the research. The SASCIS follow-up data collection was approved by the Regional Ethical Review Board in Lund, Sweden (Dnr 2016/911).

Data collection

Sociodemographics and injury characteristics

Data on sociodemographics (age, sex, marital status (dichotomized as married/co-habiting/having a partner vs single), vocational situation (dichotomized as working full-time/part-time vs not vocationally active)) and injury characteristics (time since injury, level and severity of injury, cause of injury and age at injury) were collected using a study-specific question-naire and obtained from the records of the initial data collection in 2011–2012.

Secondary health conditions

The participants were asked about the occurrence of SHCs: (i) bowel-related problems such as incontinence, constipation, diarrhea, irregularity, (ii) bladder-related

Table 1 Sociodemographics and injury characteristics of older adults with long-term spinal cord injury (n = 78).

	<i>n</i> (%); mean ± SD; median, min–max
Sex	
Men	53 (68)
Women	25 (32)
Age (years)	68 ± 8; 66, 55–88
Age at time of injury (years)	37 ± 15; 35, 7–71
Time since injury (years)	31 ± 11; 31, 15–55
Cause of injury	
Traumatic	50 (64)
Non-traumatic	28 (36)
Level and severity of injury	
Tetraplegia AIS A-C	12 (16)
Paraplegia AIS A-C	26 (33)
All AIS D	40 (51)
Marital status	
Married/co-habiting/partner	47 (60)
Single	31 (40)
Vocational situation	
Working full-time/part-time	24 (31)
Disability pension/old age	54 (69)
pension	

AIS, American Spinal Injury Association (ASIA) Impairment Scale;¹⁸ SD, standard deviation.

problems such as incontinence, urgency, frequent urinary tract infections (more than 3 times per year), (iii) spasticity and (iv) nociceptive pain and neuropathic pain rated on a standard Visual Analog Scale for pain (ranging between 0 mm (no pain) to 100 mm (worst imaginable pain)). The pain was then dichotomized as no/mild pain (VAS 0–44 mm) or moderate/severe pain (45–100 mm).²⁰

Life satisfaction

Data on life satisfaction were collected using the Life Satisfaction Questionnaire (LiSat-11).²¹ LiSat-11 is a Swedish questionnaire where the respondents rate their satisfaction with life as a whole and with 10 different life domains (*i.e.* vocational situation, financial situation, leisure situation, contacts with friends and acquaintances, sexual life, self-care, family life, partner relationship, somatic health and psychological health). Each item is scored on a 6-point scale from 1 (very dissatisfied) to 6 (very satisfied). The LiSat-11 has shown satisfactory internal consistency in persons with SCI²² and is considered valid for the general population.²¹ The LiSat-11 was sent to the participants prior to the home visit and was reviewed and collected at the visit.

Statistical analyses

The data were processed and analyzed using IBM SPSS Statistics Software version 25 (IBM Corporation, Armonk, NY, USA). Data on sociodemographics, injury characteristics and SHCs are presented as median, mean, standard deviation (SD), minimum (min), maximum (max) and percentages (%). A total number of SHCs was computed for each participant, where 0 corresponds to no SHC and 5 corresponds to the occurrence of bowel-related and bladder-related problems, spasticity and moderate/severe nociceptive and neuropathic pain. The frequencies (%) of each response option in the LiSat-11 (from very dissatisfied to very satisfied) were calculated for each life domain. The scores on LiSat-11 were dichotomized into dissatisfied (score 0-4) and satisfied (score 5-6), as suggested by the developer.²¹ To determine normality, continuous data were visually inspected using histograms. The association between the dichotomized score for satisfaction with each life domain in the LiSat-11 and sociodemographics, injury characteristics and SHCs were investigated using the χ^2 test and the Fisher's exact test for categorical data, the Mann-Whitney U-test for non-normally distributed continuous data and the independent t-test for normally distributed continuous data. A P value less than 0.05 was considered statistically significant.

Results

Sociodemographics and injury characteristics

Data on the participants' sociodemographics and injury characteristics are presented in Table 1. Among the 53 men and the 25 women, the mean age was 68 years (median 66, SD 8; min-max 55–88), the mean age at the time of injury was 37 years (median 35, SD 15; min-max 7–71) and the mean time since injury was 31 years (median 31, SD 11; min-max 15–55). In total, 64% (n = 50) had sustained a traumatic injury. A majority (n = 47, 60%) were married/co-habiting/had a partner and 31% (n = 24) were still vocationally active.

Secondary health conditions

Data on self-reported SHCs are presented in Table 2. Approximately half of the participants reported bowelrelated (n = 37; 47%) or bladder-related problems (n = 39; 50%). In total, 62% of the sample had recurring spasticity (n = 48). A majority experienced nociceptive (n = 54, 69%) and neuropathic pain (n = 49, 63%) and both pain types were moderate/severe in about half of the cases (n = 40, 51% and n = 35, 45%, respectively). The participants reported on average 2.6 SHCs (median 3, SD 1.3; range 0–5).

Life satisfaction

Data on the participants' life satisfaction are presented in Table 3. A large majority (78%) of the 78 participants were at least rather satisfied with life as a whole, 4% were dissatisfied and 1% very dissatisfied. Nearly half of the

Table 2	Secondary health conditions among older adults with
long-terr	m spinal cord injury ($n = 78$).

	<i>n</i> (%); mean ± SD, median, min – max
Bowel-related problems ^a	37 (47)
Bladder-related problems ^b	39 (50)
Spasticity	48 (62)
Nociceptive pain	54 (69)
No/mild (VAS 0–44 mm) ^c	38 (49)
Moderate/severe (VAS 45–100 mm) ^c	40 (51)
Neuropathic pain	49 (63)
No/mild (VAS 0–44 mm)	42 (54)
Moderate/severe (VAS 45–100 mm)	35 (45)
Number of secondary health conditions ^d	2.6 ± 1.3, 3, 0–5

VAS, Visual Analog Scale (0-100 mm).

^aRecurring bowel-related problems (*e.g.* incontinence,

constipation, flatulence, diarrhea, irregularity).

^bRecurring bladder-related problems (*e.g.* incontinence, urgency, time-consuming bladder management, bladder stones). ^cAccording to lensen at $a/^{20}$

^cAccording to Jensen *et al.*²⁰

^dOccurrence (0–5) of bowel-related and bladder-related problems, spasticity and moderate/severe nociceptive and neuropathic pain.

sample (46%) were satisfied to very satisfied with their vocational situation. More than one third (37%) of the participants were very dissatisfied with their sexual life and only 3% very satisfied. Of those who had a family or a partner, a majority were satisfied to very satisfied with their family life and/or partner relationship (74% and 78%, respectively). A total of 23% were satisfied to very satisfied with their somatic health while a majority (62%) were satisfied to very satisfied with their psychological health.

Associations between life satisfaction and sociodemographics and injury characteristics

Associations between satisfaction with different life domains and sociodemographics and injury characteristics are presented in Table 4. There were no significant differences between men and women in any of the life domains in LiSat-11, and there was no significant association between life satisfaction and chronological age. Participants who were satisfied with their contacts with friends and their family life had a significantly shorter time since injury compared to those who were not satisfied. With regard to level and severity of the injury, participants with an AIS D injury were significantly less satisfied with their somatic health compared to participants with either a tetraplegia AIS A-C or a paraplegia AIS A-C injury. Having a partner and being vocationally active were significantly associated with greater satisfaction with life as a whole, vocational situation and family life. In addition, a partner relationship was significantly associated with greater satisfaction with somatic health and an active vocational situation was significantly associated with greater satisfaction with sexual life and activities of daily living.

Associations between life satisfaction and secondary health conditions

Associations between satisfaction with different life domains and SHCs are presented in Table 5. Participants who reported bowel-related problems were significantly less satisfied with life as a whole, contacts with friends, family life and psychological health. Participants with moderate/severe nociceptive pain were less satisfied with life as a whole, leisure and somatic health. More SHCs were significantly associated with lower satisfaction with life as a whole, contacts with friends, somatic and psychological health.

Discussion

To the best of our knowledge, this is the first study to describe satisfaction with different life domains and associated factors in a population of older adults with

	Very satisfied (%)	Satisfied (%)	Rather satisfied (%)	Rather dissatisfied (%)	Dissatisfied (%)	Very dissatisfied (%)
Life as a whole	15	21	42	17	4	1
Vocation $(n = 72)$	18	28	28	8	7	11
Economy	24	31	23	15	4	3
Leisure	10	24	41	15	4	5
Contacts with friends	21	32	32	6	6	3
Sexual life $(n = 76)$	3	12	21	12	16	37
Activities of daily living	12	21	24	21	4	19
Family life ^a $(n = 64)$	44	30	17	3	6	-
Partner relationship ^b	52	26	13	4	4	-
(n = 46)						
Somatic health	8	15	33	22	17	5
Psychological health	31	31	22	10	5	1

Table 3 Percentages of self-reported levels of domain-specific life satisfaction among older adults with long-term spinal cord injury (n = 78).

^aThose who reported to have a family.

^bThose with a partner.

long-term SCI in the context of Northern Europe. Our hypotheses were supported as the study participants reported particularly low satisfaction with the life domains sexual life, activities of daily living and somatic health. Moreover, having a partner and being vocationally active were significantly associated with satisfaction with more life domains than injury characteristics.

Life satisfaction

A majority of the participants were at least rather satisfied with most of the 11 life domains, including life as a whole. However, only 36% were satisfied or very satisfied with life as a whole. In comparison, approximately 70% of non-injured Swedish populations of different ages report satisfaction with this life domain.^{8,21,23} Moreover, the levels of satisfaction with many life domains reported by the SASCIS sample are lower than in these samples,^{8,21,23} including the most frail older adults above the age of 80 years.⁸ Comparable results have also been reported among persons with late effects of polio (n = 169, mean age 61 years) and traumatic brain injury (n = 67, mean age 44 years).^{24,25} This indicates that persons with life-long

Table 4 Associations between self-reported levels of domain-specific life satisfaction and sociodemographics and injury characteristics among older adults with long-term spinal cord injury.

	Men/ women (%)	Age (P value)	Time since injury (P value)	Tetra AIS A-C/Para AIS A-C/All AIS D (%, P value)	Partner relationship/ no partner (%, P value)	Working full-time or part-time/not working (%, P value)
Life as a whole	38/32	-	_	58/35/30	47/19 (P = 0.017)*	54/28 (P = 0.040)*
Vocation	45/48	-	-	67/48/38	58/28 (P = 0.016)*	67/35 (P = 0.023)*
Economy	58/48	-	-	67/65/45	64/42	67/50
Leisure	38/28	-	-	58/38/25	41/26	42/31
Contacts with	53/52	-	$P = 0.043^{a_*}$	58/58/48	60/42	63/48
friends						
Sexual life	15/13	-	_	36/12/10	20/7	30/8 (P = 0.015)*
Activities of daily living	30/36	_	-	8/42/33	38/23	54/22 (P = 0.008)*
Family life	69/82	-	$P = 0.026^{b*}$	73/75/73	82/53 (P = 0.028)*	95/64 (P = 0.013)*
Partner relationship	76/85	_	_	100/76/71	80/0 (n = 35/0)	82/76
Somatic health	25/20	_	_	42/35/10 (P = 0.013) ^{c*}	34/6 (P = 0.005)*	21/24
Psychological health	62/60	_	_	21/32/47	68/52	71/57

Notes: Values are presented as percentages of very satisfied and satisfied, according to Fugl-Meyer *et al.*,²¹ and P values. Associations were investigated using the Chi-square test or the Fisher's exact test for categorical variables (*e.g.* sex). For continuous variables (*e.g.* age), participants who were satisfied were compared to those who were dissatisfied using the Mann–Whitney *U*-test.

*Statistically significant result (P < 0.05).

^aSatisfied participants exhibited a shorter time since injury.

^bSatisfied participants exhibited a shorter time since injury.

^cTetra AIS A-C/All AIS D 42/10 (P = 0.022), Para AIS A-C/All AIS D 35/10 (P = 0.025), Tetra AIS A-C/Para AIS A-C 42/35 (P = 0.73).

	Bowel-related problems/no bowel-related problems (%, P value)	Bladder-related problems/no bladder-related problems (%, P value)	Moderate or severe nociceptive pain/ mild or no nociceptive pain (%, P value)	Moderate or severe neuropathic pain/ mild or no neuropathic pain (%, P value)	Spasticity/ no spasticity (%, P value)	Number of secondary health conditions (P value)
Life as a whole	22/49 (P = 0.018)*	26/46	23/50 (P = 0.018)*	40/33	35/37	0.015*
Vocation	37/54	38/54	46/46	$61/35 (P = 0.033)^*$	50/38	-
Economy	46/63	46/64	53/58	60/52	56/53	-
Leisure	30/39	28/41	18/53 (P = 0.002)*	37/33	33/37	0.039*
Contacts with friends	32/71 (P = 0.001)*	51/54	48/58	49/57	48/60	0.024*
Sexual life	14/15	11/18	10/19	12/17	15/14	-
Activities of daily living	27/37	31/33	28/37	29/36	25/43	—
Family life	59/84 (P = 0.048)*	70/77	78/69	80/68	75/71	-
Partner relationship	67/88	73/83	80/77	85/72	82/72	-
Somatic health	14/32	13/33	13/34 (P = 0.032)*	29/19	21/27	0.021*
Psychological health	43/78 (P = 0.002)*	51/72	53/71	63/62	58/67	0.007*

Table 5 Association between self-reported levels of domain-specific life satisfaction and secondary health conditions among older adults with long-term spinal cord injury.

Notes: Values are presented as percentages of very satisfied and satisfied, according to Fugl-Meyer *et al.*,²¹ and P values. Associations were investigated using the Chi-square test or the Fisher's exact test for categorical variables (*e.g.* spasticity). For continuous variables (*i.e.* number of SHCs), participants who were satisfied were compared to those who were dissatisfied using independent t-tests; a significant P value represents significantly fewer SHCs among satisfied participants.

*Statistically significant result (P < 0.05).

neurological disabilities are likely to experience lower levels of life satisfaction than the general population, regardless of diagnosis. It can thereby be argued that rehabilitation interventions aiming to increase life satisfaction do not need to be disability-specific but instead focus on the experienced consequences of the neurological condition.

In total, 22% of the participants in our study were rather dissatisfied to very dissatisfied with their life as a whole. These persons need to be identified and provided with adequate support and counseling. During informal conversations, some participants expressed unmet needs to meet others in the same situation. This emphasizes the need to integrate community peerbased programs in long-term management and rehabilitation. Peer interaction can be of great importance throughout the lifespan for people with SCI^{26,27} and has the potential to improve life satisfaction.¹²

The lowest ratings of life satisfaction were seen in the domains sexual life, activities of daily living and somatic health. The results are not unexpected as an SCI can affect these life domains considerably. However, it is somewhat surprising that the level and severity of the injury was not significantly related to satisfaction with activities of daily living as this injury characteristic is strongly related to physical independence among older adults with long-term SCI.¹⁵ In addition, we could not find an association between satisfaction with activities of daily living and problems related to bowel and

bladder function, pain and spasticity. Again, these SHCs have been reported to impact on daily activities.^{15,28,29} The discrepancies might reflect that the actual performance of activities of daily living and satisfaction with performance differs. This emphasizes the need to address the subjective aspect of physical independence in long-term management after SCI.

The participants rated a particularly low satisfaction with sexual life where as many as 37% were very dissatisfied and only 15% were satisfied or very satisfied. Persons with SCI often experience reduced ability to achieve erection, ejaculation and lubrication during sexual activity, and the injury is also associated with reduced male fertility.^{30,31} Moreover, bowel and bladder incontinence has been reported to be negatively associated with satisfaction with sexual life after SCI, as demonstrated by Sale et al.³² These issues specific to persons with SCI most likely explain the low satisfaction with sexual life in our sample. Thus, the results emphasize the importance of assessing satisfaction with sexual life and providing adequate guidance during rehabilitation and follow-up programs for older adults with longterm SCI.

Associations between life satisfaction and sociodemographics, injury characteristics and secondary health conditions

In the present study, having a partner and being vocationally active were significantly associated with

greater satisfaction with many of the assessed life domains, including life as a whole. These associations have been reported in many previous studies, both after SCI^{9,11,12,15,33} and in the general population.^{8,21,34,35} A person's life satisfaction reflects the degree to which life goals have been attained, and working and founding a family are important life areas for many people. As expected, having a partner was significantly associated with satisfaction with partner relationship and family life, but also with the domains somatic health and vocational status. This indicates that the positive emotional effects of being in a relationship can be seen across a wide array of life domains. Likewise, the association between an active vocational situation and greater satisfaction with activities of daily living, family life and sexual life may reflect that persons who are vocationally active have greater opportunities to participate as active members in a social context. It is also likely that these individuals are more physically independent in their daily activities. Thus, the results from this study and previous findings suggest that the social environment and participation in meaningful activities are of importance for satisfaction with life many years after SCI.

Somewhat counterintuitive, we found that participants with AIS D injuries were less satisfied with their somatic health as compared to those with greater neurological impairment. However, this finding is supported by previous research showing that veterans with AIS D injuries reported more pain, lower vitality and lower general health as compared to those with tetraplegia AIS A-C and paraplegia AIS A-C injuries.³⁶ Several plausible explanations to these findings have been discussed, such as fatigue related to walking, frustration with slowness in accomplishing various tasks and feeling misunderstood due to less visible deficits (such as pain, sexual impairments and bowel-related and bladder-related problems).³⁷ Ames et al.³⁶ also found a lower global life satisfaction and more depressive symptoms in this subgroup, although an association between level and severity of injury and satisfaction with life as a whole and psychological health could not be found in the present study.

Bowel-related problems were associated with lower ratings of life satisfaction in several life domains, many of which are related to social interaction. This is in accordance with previous findings that social contacts are negatively affected as individuals experience anxiety about bowel incontinence in public areas and intimate situations, and frustration about unreliable bowel routines.³⁸ In addition, it has been reported that

persons with SCI who are satisfied with their bowel routine experience less limitations in professional and social life,³⁹ and that bowel management interferes with social life, personal relationships and the ability to leave home for recreation or work.²⁹

The finding that moderate and severe nociceptive pain was associated with lower satisfaction with life as a whole, leisure and somatic health is not surprising and supported by previous studies.^{9,40} This may reflect that nociceptive pain is often experienced in body parts susceptible to a lot of strain when ambulating using mobility aids. Hence, nociceptive pain limits mobility and community participation to a large extent, and participation restrictions are strongly related to life satisfaction.⁴¹ These results further strengthen the notion that pain and pain management should be routinely assessed in follow-up programs for older adults with long-term SCI.^{15,42,43}

Strengths and limitations

Several strengths of the SASCIS have previously been presented, such as the representative study sample and the use of reliable, valid and internationally recognized assessment tools, uniformity of data collection and very limited missing data.^{16,43} We used cross-sectional data in the analyses which limits conclusions about causal relationships between variables. With longitudinal data, we will be able to determine the predictors of global and domain-specific life satisfaction among older adults with long-term SCI. This study included individuals with varying levels and severity of SCI, which entails a generalizability of the results. This can also be regarded as a limiting factor as results are derived from a heterogeneous population in regard to these injury characteristics. However, the sample size did not permit further analyses in relation to the level and severity of the injury. In future studies, multivariable analyses are needed to confirm our results while controlling for possible confounding variables.

Conclusion

Life satisfaction can be affected many years after SCI, regardless of age and sex. The low satisfaction with sexual life, activities of daily living and somatic health calls for increased attention to these life domains in clinical practice and during long-term follow-ups. The associations demonstrate the importance of the social context, participation in meaningful activities and minimizing SHCs to maintain life satisfaction in older adults with long-term SCI.

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Conflict of interest The authors declare no conflict of interest.

Data availability All the data were archived according to the Swedish Act concerning the Ethical Review of Research Involving Humans to attain confidentiality and are available from the corresponding author upon reasonable request.

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References

- 1 Pavot W, Diener E. Review of the Satisfaction With Life Scale. Psychol Assess 1993;5:164–72.
- 2 Pavot W, Diener E. The Satisfaction With Life Scale and the emerging construct of life satisfaction. J Pos Psychol 2008;3:137–52.
- 3 Mortenson WB, Sakakibara BM, Miller WC, Wilms R, Hitzig S, Eng JJ. Aging following spinal cord injury. In: Eng JJ, Teasell RW, Miller WC, Wolfe DL, Townson AF, Hsieh JTC, et al., (eds.) Spinal Cord Injury Rehabilitation Evidence. Version 5.0. [Internet]. Vancouver. 2014 [cited 2019 February 10]. Available from https://scireproject.com/evidence/rehabilitation-evidence/ aging/
- 4 Post MW, van Leeuwen CM. Psychosocial issues in spinal cord injury: a review. Spinal Cord 2012;50:382–9.
- 5 Steptoe A, Deaton A, Stone AA. Subjective wellbeing, health, and ageing. Lancet 2015;385:640–8.
- 6 Hajek A, Konig HH. Negative health comparisons decrease affective and cognitive well-being in older adults. Evidence from a population-based longitudinal study in Germany. Front Psychol 2016;7:999.
- 7 Ratigan A, Kritz-Silverstein D, Barrett-Connor E. Sex differences in the association of physical function and cognitive function with life satisfaction in older age: The Rancho Bernardo study. Maturitas. 2016;89:29–35.
- 8 Wilhelmson K, Fritzell E, Eklund K, Dahlin-Ivanoff S. Life satisfaction and frailty among older adults. Health Psychol Res 2013;1:e32.

- 9 Adriaansen JJ, Ruijs LE, van Koppenhagen CF, van Asbeck FW, Snoek GJ, van Kuppevelt D, *et al.* Secondary health conditions and quality of life in persons living with spinal cord injury for at least ten years. J Rehabil Med 2016; 48:853–60.
- 10 Sakakibara BM, Hitzig SL, Miller WC, Eng JJ. An evidence-based review on the influence of aging with a spinal cord injury on subjective quality of life. Spinal Cord 2012;50:570–8.
- 11 Ottomanelli L, Lind L. Review of critical factors related to employment after spinal cord injury: implications for research and vocational services. J Spinal Cord Med 2009;32:503–31.
- 12 Silveira SL, Ledoux TA, Johnston CA, Kalpakjian C, O'Connor DP, Cottingham M, *et al.* Well on wheels intervention: satisfaction with life and health for adults with spinal cord injuries. J Spinal Cord Med 2018 Dec 17 [Epub ahead of print]. doi:10.1080/ 10790268.2018.1554333.
- 13 Post MW, Reinhardt JD. Participation and life satisfaction in aged people with spinal cord injury: does age at onset make a difference? Top Spinal Cord Inj Rehabil. 2015;21:233–40.
- 14 Krause JS, Newman JC, Clark JMR, Dunn M. The natural course of spinal cord injury: changes over 40 years among those with exceptional survival. Spinal Cord. 2017; 55:502–8.
- 15 Jörgensen S, Iwarsson S, Lexell J. Secondary health conditions, activity limitations, and life satisfaction in older adults with longterm spinal cord injury. PM R 2017;9:356–66.
- 16 Jörgensen S, Iwarsson S, Norin L, Lexell J. The Swedish Aging with Spinal Cord Injury Study (SASCIS): methodology and initial results. PM R 2016;8:667–77.
- 17 von Elm E, Altman DG, Egger M, Pocock SJ, Gotzsche PC, Vandenbroucke JP. Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies. BMJ. 2007;335:806–8.
- 18 Kirshblum SC, Burns SP, Biering-Sorensen F, Donovan W, Graves DE, Jha A, *et al.* International standards for neurological classification of spinal cord injury (revised 2011). J Spinal Cord Med 2011;34:535–46.
- 19 DeVivo MJ, Biering-Sorensen F, New P, Chen Y. Standardization of data analysis and reporting of results from the International Spinal Cord Injury Core Data Set. Spinal Cord. 2011;49:596–9.
- 20 Jensen MP, Chen C, Brugger AM. Interpretation of visual analog scale ratings and change scores: a reanalysis of two clinical trials of postoperative pain. J Pain 2003;4:407–14.
- 21 Fugl-Meyer AR, Melin R, Fugl-Meyer KS. Life satisfaction in 18to 64-year-old Swedes: in relation to sex, age, partner and immigrant status. J Rehabil Med 2002;34:239–46.
- 22 Post MW, van Leeuwen CM, van Koppenhagen CF, de Groot S. Validity of the Life Satisfaction questions, the Life Satisfaction Questionnaire, and the Satisfaction With Life Scale in persons with spinal cord injury. Arch Phys Med Rehabil 2012;93:1832–7.
- 23 Bergman M, Graff C, Eriksdotter M, Schuster M, Fugl-Meyer KS. Overall and domain-specific life satisfaction when living with familial Alzheimer's disease risk: A quantitative approach. Nurs Health Sci 2017;19:452–8.
- 24 Jacobsson L, Lexell J. Life satisfaction 6-15 years after a traumatic brain injury. J Rehabil Med 2013;45:1010–15.
- 25 Lexell J, Brogårdh C. Life satisfaction and self-reported impairments in persons with late effects of polio. Ann Phys Rehabil Med 2012;55:577–89.
- 26 Divanoglou A, Georgiou M. Perceived effectiveness and mechanisms of community peer-based programmes for spinal cord injuries – a systematic review of qualitative findings. Spinal Cord 2017;55: 225–34.
- 27 Molton IR, Yorkston KM. Growing older with a physical disability: A special application of the successful aging paradigm. J Gerontol B Psychol Sci Soc Sci 2017;72:290–9.
- 28 Bloemen-Vrencken JH, Post MW, Hendriks JM, De Reus EC, De Witte LP. Health problems of persons with spinal cord injury living in the Netherlands. Disabil Rehabil. 2005;27:1381–9.
- 29 Inskip JA, Lucci VM, McGrath MS, Willms R, Claydon VE. A community perspective on bowel management and quality of life after spinal cord injury: the influence of autonomic dysreflexia. J Neurotrauma 2018;35:1091–1105.
- 30 Holtz A, Levi R. Ryggmärgsskador: behandling och rehabilitering [Spinal cord injuries: treatment and rehabilitation]. Lund: Studentlitteratur; 2006.

- 31 Courtois F, Charvier K. Sexual dysfunction in patients with spinal cord lesions. Handb Clin Neurol 2015;130:225–45.
- 32 Sale P, Mazzarella F, Pagliacci MC, Agosti M, Felzani G, Franceschini M. Predictors of changes in sentimental and sexual life after traumatic spinal cord injury. Arch Phys Med Rehabil 2012;93:1944–9.
- 33 Cao Y, Krause JS, Saunders LL, Clark JM. Impact of marital status on 20-year subjective well-being trajectories. Top Spinal Cord Inj Rehabil 2015;21:208–17.
- 34 Melin R, Fugl-Meyer KS, Fugl-Meyer AR. Life satisfaction in 18to 64-year-old Swedes: in relation to education, employment situation, health and physical activity. J Rehabil Med 2003;35:84–90.
- 35 Powdthavee N. I can't smile without you: Spousal correlation in life satisfaction. J Econ Psychol 2009;30:675–89.
- 36 Ames H, Wilson C, Barnett SD, Njoh E, Ottomanelli L. Does functional motor incomplete (AIS D) spinal cord injury confer unanticipated challenges? Rehabil Psychol. 2017;62:401–6.
- 37 Jannings W, Pryor J. The experiences and needs of persons with spinal cord injury who can walk. Disabil Rehabil 2012;34:1820–6.

- 38 Braaf S, Lennox A, Nunn A, Gabbe B. Social activity and relationship changes experienced by people with bowel and bladder dysfunction following spinal cord injury. Spinal Cord 2017;55:679–86.
- 39 Pardee C, Bricker D, Rundquist J, MacRae C, Tebben C. Characteristics of neurogenic bowel in spinal cord injury and perceived quality of life. Rehab Nurs. 2012;37:128–35.
- 40 Norrbrink Budh C, Österåker AL. Life satisfaction in individuals with a spinal cord injury and pain. Clin Rehabil 2007;21:89–96.
- 41 Larsson Lund M, Nordlund A, Bernspång B, Lexell J. Perceived participation and problems in participation are determinants of life satisfaction in people with spinal cord injury. Disabil Rehabil 2007;29:1417–22.
- 42 Jörgensen S, Martin Ginis KA, Iwarsson S, Lexell J. Depressive symptoms among older adults with long-term spinal cord injury: associations with secondary health conditions, sense of coherence, coping strategies and physical activity. J Rehabil Med 2017;49: 644–51.
- 43 Jörgensen S. Older adults with long-term spinal cord injury [dissertation]. Lund: Lund University; 2017.