Participation and Life Satisfaction in Aged People with Spinal Cord Injury: Does Age at Onset Make a Difference?

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Background: Few studies have reported on outcomes in samples of elderly people with SCI and the impact of the age at onset of SCI is unclear. **Objective:** To study levels of participation and life satisfaction in individuals with SCI aged 65 years or older and to analyze differences in participation and life satisfaction scores between individuals injured before or after 50 years of age. **Methods:** This cross-sectional survey included 128 individuals with SCI who were at least 65 years old. Age at onset was dichotomized as <50 or ≥50 years of age. Participation was measured with the Frequency scale of the Utrecht Scale for Evaluation-Participation, and life satisfaction was measured with 5 items of the World Health Organization Quality of Life abbreviated form. **Results:** Participants who were injured before 50 years of age showed similar levels of functional status and numbers of secondary health conditions but higher participation and life satisfaction scores compared to participants injured at older age. In the multiple regression analysis of participation, lower current age, higher education, and having paraplegia were significant independent determinants of increased participation (explained variance, 25.7%). In the regression analysis of life satisfaction, lower age at onset and higher education were significant independent determinants of higher life satisfaction (explained variance, 15.3%). **Conclusion:** Lower age at onset was associated with better participation and life satisfaction. This study did not reveal indications for worsening participation or life satisfaction due to an accelerated aging effect in this sample of persons with SCI. **Key words:** aged, aging, quality of life, rehabilitation outcome, spinal cord injuries

Aging in the population of individuals with spinal cord injury (SCI) has 2 aspects: the average age at onset of SCI is increasing and people with SCI live on average longer than half a century ago. Age at onset of traumatic SCI has risen from 28.7 years in the 1970s to 40 years in the United States during the 2005-2009 period.¹ In other countries, a bimodal distribution of age at onset of traumatic SCI has emerged in recent years.² In the Netherlands, the median age at first admission to the acute hospital after traumatic SCI has increased to 62 years in 2010.³ People who are older at injury are more often victims of falls and have nontraumatic, incomplete, and cervical SCI more often than individuals

who are injured at a younger age.³⁻⁵ They are more vulnerable than younger people and are at greater risk of death shortly after the onset of SCI.⁶ If they survive the acute phase, they are less often referred to specialized rehabilitation hospitals.³ If referred to a specialized center, elderly people with SCI may gain a similar rate of functional improvement⁷; but because older patients generally have lower functional scores at admission, they also show worse rehabilitation outcomes compared to people who are injured at a younger age.^{4,8-10}

The life expectancy of the population with SCI has grown over the last 50 to 60 years.¹¹ Many people with a new SCI can expect to live

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another 30 to 40 years or more. However, this life expectancy has not grown in recent decades and is still clearly below that of the general population.¹¹ People with SCI are at risk of “accelerated aging” due to an inactive lifestyle and a greater risk of obesity, chronic inflammation, pressure ulcers, and pulmonary infections.^{1,12}

Participation and quality of life in aged persons with SCI are influenced by a complex interaction of many factors associated with current chronologic age, age at injury, duration of injury, and age cohort effects. It has been suggested that increasing age and being of older age at onset of SCI are independently associated with worse outcomes and that longer time after SCI is associated with better adjustment, whereas the impact of age cohort effects on adjustment is unknown.^{1,13-15} However, research into the impact of these health-related changes on participation and life satisfaction of aged people living with SCI is sparse, and associations with aging are often studied in samples that are well below retirement age.¹⁵

Only 2 longitudinal projects in aging people with SCI are available. Krause and Bozard¹⁶ described 35-year longitudinal data of 64 individuals with SCI (mean age, 61.5 years; mean time since SCI, 41.4 years). The participants rated their overall adjustment significantly higher at follow-up than they did at the first assessment 35 years before (8.4 and 7.6 on a 0-10 scale, respectively). The participants, however, showed decreases in satisfaction with social life and participation indicators (visits with others, outings).¹⁶ Charlifue and Gerhart¹⁷ found in a large sample of people with long-standing SCI (mean age, 59 years; time since onset of SCI, 36 years at follow-up) a small but significant decline in community reintegration over a period of 10 years. Life satisfaction, however, remained stable over this time period.¹⁷

It is still unclear how people aging with SCI differ from people who acquire SCI in later life.¹⁸ Given the same age, the accelerated aging hypothesis predicts that people injured at a younger age will be worse off. However, the reverse – higher age at injury is an independent predictor of worse functional outcomes – has also been shown.¹⁰ We therefore used data from earlier research with the following objectives: (a) to describe the levels of participation and life satisfaction in individuals

with SCI aged 65 years or older, and (b) to analyze differences in participation and life satisfaction between individuals injured before 50 years of age or at or after 50 years of age.

Methods

Patients

This study utilizes data collected in the International Labor Market Integration Assessment in SCI (ILIAS).¹⁹ This study was conducted in 4 European countries in 2012; here we analyze data from the Dutch sample. All members of the Dutch SCI consumer organization Dwarslaesie Organisatie Nederland (DON) with SCI were invited to participate in the Dutch part of ILIAS. All participants 65 years of age or older were included in the current analyses.

Procedure

Participants were first contacted by postal mail through DON. The package contained an invitation letter from DON, an information letter from the researchers, the questionnaire, and a prepaid return envelope. Members were encouraged to complete the questionnaire online, but they could also complete a paper and pencil version. The study protocol of the Dutch ILIAS was submitted to the Medical Ethics Committee of the University Medical Center Utrecht, and this committee declared that the protocol did not require formal ethical approval.

Instruments

Demographic variables included age, age at onset of SCI, time since SCI, gender, years of formal education, and living situation (alone versus with others). SCI characteristics included etiology of injury (traumatic vs non-traumatic), self-reported level (paraplegia vs tetraplegia) and completeness of SCI (motor incomplete vs motor complete). Functional status was measured with 5 items taken from the Spinal Cord Independence Measure III (SCIM III),²⁰ namely feeding, dressing lower body, toileting, walking moderate distances, and transfers (range, 5-28).

Six secondary health conditions (SHCs) were measured as absent or present in the preceding 12 months. Further, pain in the past week was rated using a 0 to 10 numerical rating scale; pain was considered absent in case of a score of 0 to 3 and present in case of a score of 4 or higher. The sum of the number of present SHCs including pain was computed (range, 0-7).

Life satisfaction was measured with 5 items from the abbreviated World Health Organization Quality of Life (WHOQOL-BREF).²¹ The 5 items cover satisfaction with overall quality of life and satisfaction with health, daily activities, relationships, and living conditions. All items are answered on scale from 1 (*very dissatisfied*) up to 5 (*very satisfied*), with a total score ranging from 5 up to 25. The 5 items can be combined to create a reliable and valid scale.²²

Participation was measured with the Frequency scale of the Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-P).²³ This scale includes items on the frequency of productive activities (paid work, unpaid work, education, and household duties) with 6 response categories (none up to 36 hours a week or more) and items on leisure activities (sports/exercise, going out, making day trips, and leisure activities at home) and social activities (visiting family/friends, getting visits from family/friends, and contacting others by computer/phone) with 6 response categories (none up to 19 times a month or more). The total score is the sum of the item scores that is linearly transformed into a 0 to 100 scale; higher total scores reflect more participation. To explore different domains of participation, 3 subscale scores were computed: productive activities, leisure activities, and social activities. All subscale scores have the same 0 to 100 range. The USER-P showed acceptable reproducibility and good validity in rehabilitation outpatients and good validity in a sample of community-dwelling individuals with SCI.²³⁻²⁵

Data analyses

Age at onset of SCI was dichotomized into before 50 years of age and at 50 years or older. The total number of SHCs showed a skewed distribution and was dichotomized as 0 to 2 SHCs and 3 or more SHCs.

Nonparametric statistics, median (interquartile range [IQR]), Fisher's exact test, and Mann-Whitney's *U* test were used to describe the score distributions and examine differences between participants injured before 50 years or at or after 50 years of age. Spearman correlation coefficients and multiple linear regression analyses were used to test associations between possible determinants and participation and life satisfaction corrected for confounders (demographic and SCI characteristics). Time since SCI was excluded from the multivariate regression analyses because of multicollinearity with the age and age at onset variables. All selected variables were entered simultaneously in multivariate analysis.

Results

A total of 1,127 individuals were invited for the study and 511 participated (45% response rate). Information on the membership that would allow for a nonresponse analysis was unavailable. From this study group, 128 participants were 65 years of age or older and were included in the current analyses. Demographic and SCI characteristics are displayed in **Table 1**. Sixty-five participants (50.7%) were 65 to 69 years old, 38 (29.7%) were 70 to 74 years old, and 25 (19.5%) were 75 to 84 years old. Forty-eight participants (37.8%) were injured before 50 years of age and 79 (62.2%) were injured at 50 years of age or older (1 unknown).

Participants who were injured before 50 years of age were somewhat younger and more often had a traumatic and a complete SCI. However, there were no significant differences in functional status or number of SHCs between both age-at-onset groups.

Table 2 shows participation and life satisfaction scores in both age-at-onset groups. Participants injured before 50 years of age reported higher participation and life satisfaction scores than participants injured at older ages. The strongest difference was seen in productive activities. Regarding individual items, participants injured before 50 years of age performed unpaid work (60.4% vs 26%) and household work (77.1% vs 68.9%) more often than participants injured later in life.

All participation scores were significantly associated with life satisfaction (**Table 3**). Performance of productive activities was

more strongly related to life satisfaction than performance of social activities.

Associations between potential determinants and participation are shown in **Table 4**. Higher participation scores were bivariately associated with lower current age, a longer time since injury, lower age at onset of SCI, higher

education, male gender, traumatic SCI, higher functional status, and fewer SHCs. In the multiple regression analysis, lower current age, higher education, and having paraplegia were significant independent determinants of participation, together explaining a fair amount of variance (25.7%).

Table 1. Participant characteristics

Characteristics	Onset of injury at <50 years (n = 48)	Onset of injury at ≥50 years (N = 79)	Total (n = 127)	P*
Age, years	68 (4)	70 (8)	69 (7)	.006
Age at injury, years	33.5 (20)	62 (10)	56 (22)	<.001
Time since injury, years	34 (18)	8 (8)	14 (22)	<.001
Education, years	12 (7)	12 (4)	12 (5)	.169
Gender, % male	64.6	63.3	63.8	1
Living situation, % living alone	20.8	20.5	20.6	1
Etiology of SCI, % nontraumatic	33.3	54.4	53.5	.028
Level of SCI, % paraplegia	65.2	67.1	66.3	.847
Completeness of SCI, % incomplete	41.7	60.8	53.5	.044
Functional status (SCIM-5)	17 (9)	16 (8)	16.5 (8.8)	.692
Secondary health conditions, % >2	39.6	48.1	44.9	.365

Note: Values given as median (IQR), unless otherwise indicated. SCIM-5 = five items from Spinal Cord Independence Measure III.

*Fisher's Exact test (dichotomous variables) or Mann-Whitney U test (continuous variables).

Table 2. Frequency of participation and life satisfaction between age-at-onset groups

Frequency and life satisfaction	Onset of injury at <50 years (n = 48)	Onset of injury at ≥50 years (n = 79)	Total (n = 127)	P*
Frequency				
Productive activities (0-100)	14.2 (16)	5 (10)	10 (15)	.001
Leisure activities (0-100)	37.5 (25)	40 (23.8)	40 (30.8)	.503
Social contacts (0-100)	53.3 (26.7)	46.7 (26.7)	53.3 (20)	.038
Frequency total (0-100)	31.3 (15.8)	25.2 (14.1)	29.2 (14.5)	.021
Life satisfaction (5-25)	19 (5)	18 (5)	19 (5)	.018

Note: Values given as median (IQR).

* Mann-Whitney U test.

Table 3. Spearman correlations between participation and life satisfaction (N = 128)

	Leisure activities	Social activities	Frequency total	Life satisfaction
Productive activities	.34	.29	.73	.34
Leisure activities	—	.41	.72	.25
Social contacts		—	.70	.18*
Frequency total			—	.35

*All correlations

Table 4. Bivariate and multivariate analysis of determinants of participation

	Spearman correlation	Regression coefficient β	Standard error	Standardized regression coefficient	Uniquely explained variance (%)
Age, years	-.32**	-.51*	.20	-.23*	5.9
Age at onset of SCI (≥ 50 years)	-.21*	-1.53	1.99	-.07	1
Education, years	.32**	.89**	.25	.30**	10.4
Gender, male	.20*	3.22	1.8	.14	2.6
Etiology of SCI (nontraumatic)	-.13	-2.48	2.20	-.12	1.1
Level of SCI (paraplegia)	.12	4.59*	2.27	.20*	3.6
Completeness of SCI (incomplete)	.06	2.10	1.91	.10	1.1
Total explained variance					25.7

Note: NA = not applicable.

* $P < .05$. ** $P < .01$.

Higher life satisfaction scores were bivariate associated with a longer time since injury, lower age at onset, higher education, having traumatic SCI, and having fewer SHCs (**Table 5**). In the multiple regression analyses, only lower age at onset and higher education were significant independent determinants of life satisfaction, and the amount of explained variance was low (15.3%).

Discussion

As far as we know, this is the first study to examine differences in participation and life satisfaction between subgroups of age at onset of injury in aged persons with SCI. Participants injured before 50 years of age reported higher participation and life satisfaction scores than participants who were injured at an older age. In the multiple regression analyses, onset of SCI before 50 years of age was a determinant of higher life satisfaction but not of participation.

Age at onset

Participants injured at a younger age showed better participation and life satisfaction outcomes than participants injured at an older age. Participants injured at a younger age, however, also showed similar levels of functional independence despite more often having a complete SCI. This finding seems to contradict the concept of accelerated aging,^{1,15} in which the group injured at younger age is expected to show worse outcomes because

they have lived more years in the accelerated aging stage (34 vs 8 years) than the group injured at older age, who can be thought of as equally healthy as members of the general population until the onset of their SCI. Several explanations of this surprising finding are possible. Effects of accelerated aging may manifest themselves at an even older age. It is also possible that the group injured at a younger age have had more time to adapt to the SCI, although people in the group injured at older age have also had time to adapt to the SCI. Alternatively, people injured at younger age might have received more intensive rehabilitation and reintegration efforts than the group injured at older age. A recent study, however, found that people aged 60 years and older had an even longer rehabilitation stay than younger patients, probably to compensate for their higher vulnerability.⁹ Another possible explanation is that the survivor effect, that is, those with better outcomes are more likely to survive and participate in the study, might be more pronounced in the group of participants who were injured at a younger age (<50 years).¹⁶

The largest difference between the 2 age-at-onset groups was found for frequency of productive activities, in particular unpaid work and household duties. One possible explanation is that people injured at a younger age may have had more time to take up productive activities after the onset of SCI. However, median time after SCI was still 8 years in the group of people injured at an older age, so these people also had plenty of time to return to productive activities. Alternatively,

Table 5. Bivariate and multivariate analysis of determinants of life satisfaction

	Spearman correlation	Regression coefficient β	Standard error	Standardized regression coefficient	Uniquely explained variance (%)
Age, years	.05	.10	.06	.06	2.6
Age at onset of SCI (≥ 50 years)	-.21*	-1.21*	.58	-.20*	3.8
Education, years	.26**	.17*	.07	.21*	4.6
Gender (male)	.03	.14	.54	.02	0
Etiology of SCI (nontraumatic)	-.29**	-1.06	.64	-.18	2.5
Level of SCI (paraplegia)	.00	.93	.66	.15	1.8
Completeness of SCI (incomplete)	.00	.34	.55	.06	0
Explained variance					15.3

Note: NA = not applicable.

* $P < .05$. ** $P < .01$.

the group of people injured at a younger age might have been more motivated to perform these activities or might have assumed that participation in productive activities was a way to gain self-esteem and respect, especially if they were not able to return to paid work.²⁶ Thus, it is more likely that participants who were injured before 50 years old would continue these productive activities as they grew older than it is for participants injured at an older age to take up these activities. Unfortunately, we are not able to empirically examine this assumption since we do not know when these activities were performed.

We could not find other studies in which subgroups of age at onset were studied in aged persons with SCI, so we are not able to compare our results with those of other studies.

Participation

The median USER-P frequency score found in our study was below the median of 35 found in participants aged 18 to 64 years in the Dutch ILIAS study [unpublished observation] and also lower than the median of 36.1 reported in another SCI study with lower mean age (mean age, 50.6, mean time since onset of SCI, 25.3 years).²⁵ In that study, only the total frequency score was reported, which precludes a detailed comparison; but it is likely that retirement from paid employment is not compensated by a subsequent increase in other productive activities.

Life satisfaction

The median life satisfaction score found in our study was similar to the mean of 19.0 found in an international SCI study²⁷ and was even somewhat above the median of 18 found in participants aged 18 to 64 years in the Dutch ILIAS study [unpublished observation]. As in other studies, our study shows that it is possible to retain good life satisfaction even at older ages and many years after SCI.^{16,17}

Participation and life satisfaction

Levels of participation were associated with levels of life satisfaction. However, these correlation coefficients were of moderate size, and the correlation coefficient between social contacts and life satisfaction was not significant. Another study in elderly people with SCI (43–84 years of age) found few correlations between participation and life satisfaction.¹⁷ In other studies, however, moderate to strong correlations between participation and life satisfaction have been found. The most likely explanation for our result is that we measured the frequency of participation and not participation restrictions or satisfaction with participation. Subjective participation is more likely to have a high correlation with life satisfaction.²⁸

Determinants

We found higher age to be associated with a lower frequency of participation, but not with

lower life satisfaction. A decline of participation but stable or even increasing life satisfaction with increasing age has also been reported in other studies.^{16,17} Charlifue and Gerhart found age to be an independent predictor of various participation scores, but their sample had a wider age range of 43 to 83 years.¹⁷ Even in the current study with a restricted age range (>65), this association between age and participation was found. It is less surprising that we did not find an association between age and life satisfaction.^{16,17} It has been suggested that individuals with SCI are able to engage in fewer yet more life-enriching activities and to separate their compromised physical functioning from their psychological well-being due to a response shift.^{1,15,17}

Level of education is a consistent determinant of positive outcomes in SCI research. Education can be seen as a proxy variable for personal and material resources, as higher education has been shown to be associated with having a healthier lifestyle, a better job, and a higher income and living in a better neighborhood.²⁹

Limitations

The current study is based on self-report data; information on injury characteristics and SHCs was of limited accuracy and precision. Also, no information on comorbidity was collected.

Only members of the Dutch consumer organization were included, slightly fewer than half of those invited took part, and we were not able to perform a nonresponse analysis, which limits the ability to generalize our results to the entire SCI population.

Further, this was a cross-sectional study, and it is difficult to study time effects in studies with this design. Prospective longitudinal studies are better suited to analyze longitudinal effects, but even results of those studies are biased due to the survivor effect, meaning that individuals with the most favorable characteristics are more likely to survive and take part in research.¹⁶ The survivor effect is likely to have obscured the real impact of SCI on participation and life satisfaction of those affected. This effect is present in both age-at-onset groups in our study but not in the same way, and it is difficult to estimate how this effect may have affected the comparisons between groups.

Conclusion

We found generally positive participation and life satisfaction scores. Participation scores were somewhat lower than those found in other studies, but life satisfaction scores were similar. Lower age at onset was associated with better participation and life satisfaction. We did not find indications for an accelerated aging effect in this sample of aged persons with SCI.

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