

WORK PARTICIPATION AMONG PERSONS WITH TRAUMATIC SPINAL CORD INJURY AND MENINGOMYELOCELE¹

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Objective: To study injury-related and individual factors as predictors of work participation in persons with traumatic and congenital spinal cord injury.

Design: Cross-sectional questionnaire study.

Subjects: One hundred and eighty-two persons with traumatic spinal cord injury treated in the Spinal Injuries Unit in Sahlgrenska University Hospital, Göteborg, Sweden, and 48 persons with meningomyelocele admitted to the Young Adult Teams in Göteborg, Borås and Skövde, Sweden.

Methods: A structured questionnaire was sent by post. Main outcome variable was participation in work. Logistic regression modelling was used to study the associations between the potential predictors and work participation.

Results: Employment rates were 47% in the traumatic spinal cord injury group and 38% in the meningomyelocele group. The presence of other somatic or mental disorder, and neuropathic pain decreased work participation among the men with traumatic spinal cord injury. Among persons with meningomyelocele, better ambulatory status and higher educational level increased work participation. In all groups higher independence in daily activities increased the probability of work participation. According to multivariable modelling carried out for the men with traumatic spinal cord injury, age over 55 years and the presence of mental disorder decreased work participation.

Conclusion: Our data show that work participation is affected by individual and injury-related factors. Of the latter, many can be affected by rehabilitation.

Key words: spinal cord injuries, meningomyelocele, rehabilitation, employment.

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INTRODUCTION

Gainful employment is an important part of adult life. In addition to providing financial security, it also provides an environment for social interaction and a sense of self-esteem. The results from different studies indicate that participation in work has a positive effect on quality of life (1–5). It is also well-known that long-term non-participation at work has detrimental consequences on mental and physical health (6). Previous studies have shown that employment is associated with overall well-being also among persons with spinal cord injury (SCI) (7, 8). As survival rates continue to increase for persons with SCI, the need for improved educational and vocational planning also increases. To improve the vocational outcome of persons with SCI it is essential to determine which factors affect work participation and job retention within this patient group.

Among persons with traumatic SCI the overall employment rates have varied between 9% and 80% during the last decades (9–13). This wide variation between different studies is due mainly to different study designs and inclusion criteria. Previous studies have shown that higher chronological age and higher age at injury onset are associated with lower employment rates, whereas longer time since injury predicts better outcome. In a large study ($n=2980$) from the USA the employment rate was only 14% 1 year post-injury, whereas it was nearly 40% more than 20 years after the injury (9). The results concerning the association between the neurological level of the injury and work participation are somewhat inconsistent (9). The only modifiable factor that has been widely studied is education and in the majority of studies more years of education has predicted better work participation (7, 9, 13, 14). Few studies have dealt with the effects of medical problems related to SCI or the effects of other mental or somatic disorders on work participation. In a study carried out in subjects with paediatric-onset SCI, there was a greater number of injury-related medical complications among the unemployed group when compared with those who were employed (7).

There are few data concerning work participation among persons with meningomyelocele. The overall employment rates have varied from 19% to 53% (15–21). In a British cohort study, 26% of persons with meningomyelocele were in open employment (16). A somewhat higher employment rate was reported from Ireland, where 34% of a clinical spina bifida

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population, with or without shunt, were in open employment (15). Only a few studies have addressed the factors affecting employability in persons with meningomyelocele. The results concerning the role of functional impairments have been somewhat inconsistent. In one study no association was found between physical capacity or ambulatory status and work participation, whereas in another study the chances of being employed tended to decrease with increasing disability (18, 20). In one study, in which patients with the lowest intelligence had been excluded, higher intelligence, better educational level, and higher independence in toileting predicted participation in work (18). There is also evidence that family environment and behavioural functioning affect participation in work in persons with meningomyelocele (17, 18).

The aim of this study was to determine whether subject characteristics, injury-related factors, medical problems related to injury, other disorders, and vocational history affect participation in work among 2 groups of persons with functional impairments, traumatic SCI and meningomyelocele. We also wanted to describe the type of industry, and types of employment carried out by these subjects, as well as satisfaction with current work situation, quality of life, and bullying at work.

MATERIAL AND METHODS

A structured questionnaire was sent to all persons with traumatic SCI between 18 and 65 years of age who had sustained injury at least 2 years earlier and had been treated in the Spinal Injuries Unit in Sahlgrenska University Hospital, Göteborg, Sweden since 1982 ($n=370$). A slightly modified questionnaire was sent to all persons with meningomyelocele who had been admitted to the Young Adult Teams in Göteborg, Borås and Skövde, Sweden ($n=81$). Of these, 185 (50.0%) subjects with traumatic SCI and 48 (59.3%) subjects with meningomyelocele responded to the questionnaire. Three persons with traumatic SCI were excluded from the study because they did not answer the question about current employment status. Thus, the final study group comprised 182 (49.2%) persons with traumatic SCI and 48 (59.3%) persons with meningomyelocele.

The characteristics of those who were included in the study ($n=182$ and $n=48$), and the non-responders ($n=188$ and $n=33$) are shown in Table I. The study groups did not differ markedly with regard to gender or neurological level of the injury. The respondents were somewhat older than the non-respondents in the traumatic SCI group.

The main outcome variable was current employment status, which was investigated by a question with several categories. In the analyses we used a dichotomous variable (participating in work, non-participating in work). Those with full-time or part-time employment, as well as entrepreneurs, were considered as participating in work. Since the number of full-time students was insufficient ($n=6$ in the traumatic SCI group and $n=10$ in the meningomyelocele group) to keep them as separate groups, they were included in those participating in work, assuming that full-time studies lead to work participation. One person with meningomyelocele who was on parental leave was considered as participating in work in the analyses since this person had a permanent job. In Sweden an employer can apply for wage supplements from the government in order to enhance work participation among persons with functional impairments. Thirty percent of the men and 55% of the women in the traumatic SCI group, and 86% of the men and 42% of the women in the meningomyelocele group had this type of employment. Since this kind of support covers only part of the employment costs and the employer has to pay the rest, we considered these persons as participating in work. On the other hand, those in sheltered work were not considered as participating in work since this type of employment is not gainful.

The questions used to assess the independent variables and the variables used in the analyses are presented in Table II. Since our study was based on self-reported data, the International Standards for Neurological Classification of SCI by the American Spinal Injury Association (ASIA) could not be followed to determine the neurological level of the injury. The ambulatory status was inquired with a question with 4 categories according to Hoffer et al. (22). We used a Self-Reported Functional Measure (SRFM), which has been shown to be a reliable and valid instrument to assess functional independence in persons with spinal cord dysfunction (23, 24). This instrument consists of 13 items covering independence in various daily activities, categorized into 4 levels: 1 = total help or never do, 2 = some help, 3 = extra time or special tool needed, and 4 = no extra time or help. The total score of the SRFM is the sum of the scores for the individual items (range 13–52). In the analyses we dichotomized the material by using the median (sum score = 46) as the cut-off point.

Different somatic disorders potentially affecting participation in work were assessed by separate questions. A combined dichotomous variable (at least one somatic disorder, no other somatic disorders) was used in the analyses. The presence of eating disorders was assessed by a separate question, but in the analyses those with eating disorders were included in the mental disorder group. Narcotic abuse was investigated by 9 separate questions. A combined dichotomous variable concerning narcotic abuse (yes, no) was used in the analyses. Those reporting only use of marijuana or glue 1–5 times were not considered to be narcotic abusers.

Level of education was assessed by a question with several categories. In the analyses a 3-level variable was used (primary, secondary, tertiary). Primary level consisted of those who had only elementary/comprehensive school level education or less, secondary level consisted of those who had high-school or occupational school diploma, and tertiary level

Table I. Subject characterization

| | Traumatic spinal cord injury | | | Meningomyelocele | | |
|-------------------------------------|------------------------------|-------------------------------|----------|---------------------------|------------------------------|----------|
| | Study group ($n=182$) | Non-responders ($n=188$) | <i>p</i> | Study group ($n=48$) | Non-responders ($n=33$) | <i>p</i> |
| Gender | | | | | | |
| Men % (n) | 73.6 (134) | 77.1 (145) | ns | 52.1 (25) | 48.5 (16) | ns |
| Women% (n) | 26.4 (48) | 22.9 (43) | | 47.9 (23) | 51.5 (17) | |
| Mean age (range) (years) | 44.7 (21.8–64.2) | 41.1 (19.4–62.8) | 0.001 | 30.2 (19.6–50.5) | 28.4 (18.4–41.4) | ns |
| Mean age at injury (range) (years)* | 30.5 (2.1–59.4) | | | | | |
| Neurological level [†] | | | | | | |
| Cervical | 47.2% ($n=85$) | 51.5% ($n=70$) | ns | | | |
| Thoracic | 32.2% ($n=58$) | 33.1% ($n=45$) | | | | |
| Lumbar/sacral | 20.6% ($n=37$) | 15.4% ($n=21$) | | | | |

* $n=179$.

[†] $n=180$ for the study group and $n=136$ for the non-responder group.

Table II. Potential risk factors of non-participation in work

| Original variable | Classification in analysis |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------|
| Subject characteristics | |
| Gender (man/woman) | Man, Woman |
| Age (years) | ≤35, 36–45, 46–55, >55 |
| Age at injury (years) | <25, 25–40, >40 |
| Time since injury (years) | <10, 10–20, >20 |
| Injury-related factors | |
| Neurological level | Thoracic/ lumbar/ sacral, Cervical |
| Presence of brain injury (for subjects with traumatic spinal cord injury) | No, Yes |
| Presence of hydrocephalus (for subjects with meningomyelocele) | No, Yes |
| Ambulatory status (22) | Community ambulator (1), Functional ambulator (2), Non-functional ambulator (3) Non-ambulator (4) |
| Functional capacity (Self-reported Functional Measure) (23, 24) Need for assistance in the following activities (1 =Total help or never do, 2 =Some help, 3 =Extra time or special tool, 4 =No extra time or help) | Sum score >46, Sum score ≤46 |
| Moving around inside one's house | |
| Going up and down a flight of stairs | |
| Transferring to and from bed or chair | |
| Getting on and off the toilet | |
| Transferring from the shower or tub | |
| Eating | |
| Grooming | |
| Taking a bath | |
| Dressing upper body | |
| Dressing lower body | |
| Toileting | |
| Managing bladder | |
| Managing bowel | |
| Medical problems related to injury | |
| Neuropathic pain—days with pain during the preceding 12 months (1 =none, 2 =1–7 days, 3 =8–30 days, 4 =more than 30 days) | ≤30 days (1–3), >30days (4) |
| Frequency of urinary incontinence | Never, Sporadic/monthly, Weekly/daily |
| Frequency of faecal incontinence | Never, Sporadic/monthly, Weekly/daily |
| Other disorders | |
| Somatic disorder | |
| Cancer | No, Yes |
| Stroke | |
| Epilepsy | |
| Pulmonary disease | |
| Heart disease | |
| Mental disorder | |
| Mental disorder | No, Yes |
| Eating disorder | |
| Narcotic abuse | |
| Frequency of using (1 =never, 2 =1–5 times, 3 =more than 6 times) the following substances: Marijuana/hashish, Ecstasy, Amphetamine/metamphetamine, Cocaine/crack, Heroin/morphine, Subutex (buprenorfinhydrochloride)/Temgesic (buprenorfinhydrochloride), Other medicines, LSD, Thinner/glue | No (1), Yes (2–3) |
| Vocational history | |
| Education (1 =elementary/comprehensive school, 2 =vocational school, 3 =2-year high school, 4 =3–4 -year high school, 5 =university/college) | Tertiary level (5), Secondary level (2–4), Primary level (1) |
| Employment status at the time of injury (1 =full-time employment, 2 =part-time employment, 3 =entrepreneur, 4 =studying, 5 =vocational rehabilitation, 6 =sick leave >3 months, 7 =retired with special agreement, 8 =disability pension, 9 =military service, 10 =parental leave, 11 =unemployed) | Participating in work (1–3), Studying (4, 5, 9, 10), Non-participating in work (6, 7, 8, 11) |
| Vocational rehabilitation (1 =counselling, 2 =re-education, 3 =on-the-job-training, 4 =courses, 5 =none) | Yes (1–4), No (5) |

consisted of those with university or post-secondary degree. Employment status at the time of injury was assessed by a question with several categories. A 3-level variable was used in the analyses (participating in work, studying, not participating in work). Two subjects with traumatic SCI who were at vocational rehabilitation at the time of the injury were considered as studying. The unemployed or those receiving disability

pension were considered as non-participating in work. One subject with traumatic SCI who was retired with special agreement was also considered as non-participating in work. Those who were younger than 20 years at the time of injury were excluded from the analysis concerning work at injury since most of them were studying at primary or secondary level.

Satisfaction with current work situation was investigated by a 5-level question (very good, rather good, moderate, rather poor, very poor). Quality of life was assessed by using a numerical scale from 0 (dissatisfied) to 10 (satisfied).

This study was approved by the Ethics Committee of Göteborg University.

Statistical analysis

The traumatic SCI group and the meningocele group were analysed separately. We looked first at the univariate association between each independent variable and the outcome. We calculated univariate logistic regression models separately for the men and women in the traumatic SCI group. In the meningocele group the men and women were kept together in the analyses, due to a small number of participants. Odds ratios (OR) with 95% confidence intervals (CI) were computed. Due to the limited number of participants with meningocele and women with traumatic SCI the multivariable modelling was carried out only for the men with traumatic SCI. The final logistic model was fitted by using risk factors of primary interest that had shown association in the preliminary analyses. The goodness of fit of the model was evaluated by the Hosmer & Lemeshow's method (25). The Mann-Whitney test was used to test differences in quality of life (26). Statistical analyses were carried out with SPSS version 12.0.1 statistical software.

RESULTS

Traumatic spinal cord injury

Forty-eight percent of the men ($n=64$) and 46% of the women ($n=22$) were employed. Three percent ($n=4$) of the men and 4% ($n=2$) of the women were studying. The majority of the subjects had office work in administration or dissemination of information (50 of 77). Thirteen persons were employed within manufacturing, 7 within health service, and 3 within service industry.

In the univariate models the risk of non-participation in work was increased for the men older than 55 years. In the women there was no association between age and work participation. In the men the risk of non-participation in work was higher among those who had sustained injury at an age older than 40 years, whereas age at injury did not affect work participation among the women. There was a tendency for the men injured more than 10 years ago to be more often at work than those with more recent injuries. Dichotomizing time since injury at 10 years gave an OR of 0.49 (CI 0.24, 1.03). In the women time since injury did not affect work participation (Table III).

Neurological level or ambulatory status did not affect work participation in the men or in the women with traumatic SCI (Table III). Additional analyses of ambulatory status controlling for neurological level did not show differences in work participation between ambulating and non-ambulating subjects either in the men or the women. There was a tendency for brain injury to increase the risk of non-participation in work among the men with traumatic SCI. Among the women there were only 2 subjects with brain injury and neither of these was participating in work. A low SRFM score increased the risk of non-participation both in the men and women (Table III).

Neuropathic pain increased the risk of non-participation in work in the men but not in the women. Neither urinary nor faecal incontinence was associated with work participation. However, among the women there were only 2 subjects who

suffered from faecal incontinence weekly or daily and neither of these women was at work. The presence of other somatic or mental disorder increased the risk of non-participation in work in the men. Also, among the women those with other somatic disorder tended to participate in work less frequently than those without other somatic disorder. The presence of mental disorder did not affect work participation in the women. Narcotic abuse showed no effect either in the men or the women (Table III).

The men with primary level education tended to participate less frequently in work than the men with higher educational level. None of the 8 women who had only primary level education were participating in work. The risk of non-participation in work seemed to be increased, although not statistically significantly, among the men who were not at work at the time of injury when compared with those who were working at the time of injury. There were only 2 women who were not at work at the time of injury and neither of them was at work at the time of the study (Table III).

The multivariable models for men were first run including age, SRFM, neuropathic pain, presence of other somatic disorder, presence of mental disorder, and vocational rehabilitation. In this model, the OR for somatic disorder that was positive in the univariate model changed to negative. A further scrutiny revealed that this change occurred when somatic disorder was modelled together with age, mental disorder, and SRFM. This suggested correlation between somatic disorder and the mentioned variables or the combination of them. Therefore, to avoid multicollinearity, we omitted somatic disorder from the final model. In the final multivariable model only age older than 55 years and presence of mental disorder remained statistically significant risk factors of non-participation in work. The effect of SRFM approached statistical significance (Table IV).

The reason most often reported as an obstacle to work participation was the severity of the injury (reported by 70% of the men and 50% of the women). Approximately half of the participants considered injury-related medical problems and health problems as hinders for their work participation. Thirty percent reported lack of motivation as a hinder for their work participation. Nearly half (38 of 84) of those who were currently employed reported that some changes had been made at their workplace to improve accessibility. Five persons considered these changes as insufficient and another 5 persons had been forced to change workplace due to problems with accessibility.

Eight percent ($n=9$) of the men and 5% ($n=2$) of the women with traumatic SCI reported that they had been bullied at work. In the majority of cases (7 of 11) the bullying was due to the person's functional impairments. In the traumatic SCI group 79% (50 of 63) of the men and 81% (17 of 21) of the women rated satisfaction with their current work situation as very or rather good. Those participating in work reported better quality of life than the non-participants. This was seen both for men and women (Mann-Whitney U test, $p=0.001$ and $p=0.018$, respectively) (Fig. 1a).

Table III. Risk of non-participation in work in subjects with traumatic spinal cord injury (n=164–182) and meningomyelocele (n=41–48). Univariate associations from logistic regression modelling

| | | Traumatic spinal cord injury | | | | Meningomyelocele | |
|-------------------------------------------|----------------------------------------------------|------------------------------|---------------|-------|---------------|------------------|---------------|
| | | Men | | Women | | OR | 95 % CI |
| | | OR | 95 % CI | OR | 95 % CI | | |
| Subject characteristics | | | | | | | |
| <i>(n = SCI men/SCI women/MMC)</i> | | | | | | | |
| Age (years) | ≤ 35 (n = 27/15/33) | 1.00 | | 1.00 | | 1.00 | |
| | 36–45 (n = 40/12/12) | 0.40 | (0.14, 1.10) | 0.89 | (0.19, 4.00) | 0.24 | (0.05, 1.27) |
| | 46–55 (n = 35/9/3) | 0.55 | (0.20, 1.52) | 1.09 | (0.21, 5.76) | 2.40 | (0.20, 29.13) |
| | > 55 (n = 32/12/0) | 5.01 | (1.49, 16.93) | 0.63 | (0.14, 2.89) | | |
| Age at injury (years) | < 25 (n = 57/20) | 1.00 | | 1.00 | | | |
| | 25–40 (n = 46/14) | 1.10 | (0.50, 2.45) | 0.75 | (0.19, 2.96) | | |
| | > 40 (n = 29/13) | 10.71 | (3.28, 35.04) | 1.17 | (0.29, 4.73) | | |
| Time since injury (years) | < 10 (n = 45/15) | 1.00 | | 1.00 | | | |
| | 10–20 (n = 56/24) | 0.50 | (0.23, 1.11) | 0.48 | (0.13, 1.77) | | |
| | > 20 (n = 31/8) | 0.48 | (0.19, 1.22) | 0.67 | (0.12, 3.76) | | |
| Injury-related factors | | | | | | | |
| Neurological level | Thoracic/lumbar/sacral (n = 69/26) | 1.00 | | 1.00 | | | |
| | Cervical (n = 63/22) | 1.35 | (0.68, 2.68) | 1.97 | (0.62, 6.24) | | |
| Brain injury/hydrocephalus | No (n = 112/42/10) | 1.00 | | 1.00 | | 1.00 | |
| | Yes (n = 8/2/38) | 3.46 | (0.67, 17.90) | | | 1.70 | (0.38, 7.59) |
| Ambulatory status | Community ambulator (n = 35/17/9) | 1.00 | | 1.00 | | 1.00 | |
| | Functional ambulator (n = 8/3/9) | 4.50 | (0.79, 25.57) | | | 2.29 | (0.17, 30.96) |
| | Wheelchair/Non-functional ambulator (n = 85/28/30) | 1.40 | (0.63, 3.11) | 1.03 | (0.31, 3.43) | 9.14 | (1.01, 82.44) |
| Self-Reported Functional Measure | Sum score > 46 (n = 59/21/25) | 1.00 | | 1.00 | | 1.00 | |
| | Sum score ≤ 46 (n = 59/21/21) | 3.57 | (1.66, 7.64) | 8.53 | (2.16, 33.72) | 10.50 | (2.58, 42.68) |
| Medical problems related to injury | | | | | | | |
| Neuropathic pain | ≤ 30 days (n = 66/21) | 1.00 | | 1.00 | | | |
| | > 30 days (n = 63/24) | 2.66 | (1.31, 5.42) | 1.10 | (0.34, 3.55) | | |
| Urinary incontinence | Never (n = 37/17/12) | 1.00 | | 1.00 | | 1.00 | |
| | Sporadic/Monthly (n = 53/17/19) | 1.22 | (0.53, 2.83) | 1.00 | (0.26, 3.85) | 1.75 | (0.35, 8.71) |
| | Weekly/Daily (n = 42/12/15) | 1.18 | (0.49, 2.85) | 0.44 | (0.10, 2.06) | 3.43 | (0.66, 17.93) |
| Faecal incontinence | Never (n = 34/20/10) | 1.00 | | 1.00 | | 1.00 | |
| | Sporadic/Monthly (n = 87/24/27) | 1.73 | (0.77, 3.89) | 1.22 | (0.37, 4.02) | 1.60 | (0.34, 7.60) |
| | Weekly/Daily (n = 11/2/8) | 1.94 | (0.49, 7.66) | | | 2.33 | (0.34, 16.18) |
| Other disorders | | | | | | | |
| Somatic disorder | No (n = 117/40/39) | 1.00 | | 1.00 | | 1.00 | |
| | Yes (n = 13/7/9) | 3.71 | (1.13, 12.19) | 4.81 | (0.88, 26.30) | 2.24 | (0.61, 8.16) |
| Mental disorder | No (n = 111/37/39) | 1.00 | | 1.00 | | 1.00 | |
| | Yes (n = 15/10/9) | 5.25 | (1.40, 19.65) | 1.06 | (0.26, 4.27) | 1.28 | (0.30, 5.54) |
| Narcotic abuse | No (n = 110/46/46) | 1.00 | | 1.00 | | | |

Table III (Continued)

| | Traumatic spinal cord injury | | | | | |
|------------------------------------------|------------------------------|---------------|------|---------------|-------|----------------|
| | Men | | | Women | | |
| | OR | 95% CI | OR | 95% CI | OR | 95% CI |
| Yes (<i>n</i> = 18/21) | 1.75 | (0.63, 4.86) | 1.00 | (0.06, 16.97) | | |
| Vocational history | | | | | | |
| Education | | | | | | |
| Tertiary level (<i>n</i> = 34/27/9) | 1.00 | | 1.00 | | 1.00 | |
| Secondary level (<i>n</i> = 75/13/32) | 1.39 | (0.61, 3.16) | 2.33 | (0.60, 9.02) | 5.47 | (0.61, 49.17) |
| Primary level (<i>n</i> = 22/8/6) | 2.06 | (0.79, 6.14) | | | 40.00 | (2.01, 794.27) |
| Employment status at the time of injury* | | | | | | |
| At work (<i>n</i> = 90/30) | 1.00 | | 1.00 | | | |
| Studying (<i>n</i> = 6/3) | 0.18 | (0.02, 1.63) | 2.29 | (0.19, 27.99) | | |
| Not at work (<i>n</i> = 7/2) | 5.49 | (0.64, 47.46) | | | | |
| Vocational rehabilitation | | | | | | |
| Yes (<i>n</i> = 45/19/12) | 1.00 | | 1.00 | | 1.00 | |
| No (<i>n</i> = 84/28/30) | 2.19 | (1.04, 4.62) | 1.11 | (0.35, 3.57) | 0.70 | (0.18, 2.77) |

*Only subjects older than 20 years at the time of injury are included.
OR = Odds Ratio, CI = Confidence Interval.

Meningomyelocele

Twenty-eight percent (*n* = 7) of the men and 52% (*n* = 12) of the women with meningomyelocele were employed. Twenty-four percent (*n* = 6) of the men and 17% (*n* = 4) of the women were studying. The type of industry was most often administration (8 of 19). Four persons were employed within health service, 3 within dissemination of information, 2 within service industry and 2 within manufacturing.

Age did not affect work participation among the subjects with meningomyelocele, neither did concomitant hydrocephalus. Use of a wheelchair for ambulation as well as a low SRFM score markedly increased the risk of non-participation. No significant association was found between frequency of urinary or faecal incontinence and work participation. The presence of somatic or mental disorders did not affect work participation among persons with meningomyelocele. Narcotic abuse could not be analysed properly due to a small number of users. However, the only person with meningomyelocele who was classified as a narcotic abuser was not at work. Primary level of education as the highest educational level reached, increased the risk of non-participation in work (Table III).

A lack of employment possibilities was most often reported as an obstacle to work participation (reported by 44% of the men and 57% of the women). Thirty-three percent of the men and 43% of the women considered health problems as an obstacle to work participation. Thirty percent of the men but none of the women considered lack of motivation as an obstacle to their work participation. Half (9 of 18) of those who were currently employed reported that some changes had been made at their workplace to improve accessibility. Two persons considered these changes as insufficient and one person had been forced to change workplace due to problems with accessibility.

Six percent (*n* = 1) of the men and 14% (*n* = 3) of the women with meningomyelocele reported that they had been bullied at work. Two of the women who had been bullied reported that bullying had been due to their functional impairments. Fifty-seven percent (*n* = 4) of the men and 83% (*n* = 10) of the women

Table IV. Risk of non-participation in work from multivariable logistic regression model in the men with traumatic spinal cord injury (OR = odds ratio, CI = confidence interval)

| | | OR | CI |
|---------------------------|----------------|------|---------------|
| Age (years) | ≤ 35 | 1.00 | |
| | 36–45 | 0.36 | (0.10, 1.31) |
| | 46–55 | 0.32 | (0.08, 1.24) |
| | > 55 | 5.67 | (1.14, 28.23) |
| SRFM Measure | Sum score > 46 | 1.00 | |
| | Sum score ≤ 46 | 2.60 | (0.98, 6.89) |
| Neuropathic pain | ≤ 30 days | 1.00 | |
| | > 30 days | 2.07 | (0.74, 5.76) |
| Mental disorder | No | 1.00 | |
| | Yes | 5.27 | (1.06, 26.17) |
| Vocational rehabilitation | Yes | 1.00 | |
| | No | 1.42 | (0.49, 4.05) |

Hosmer & Lemeshow goodness of fit test: *p* = 0.38 (25).
SRFM: Self-Reported Functional Measure.

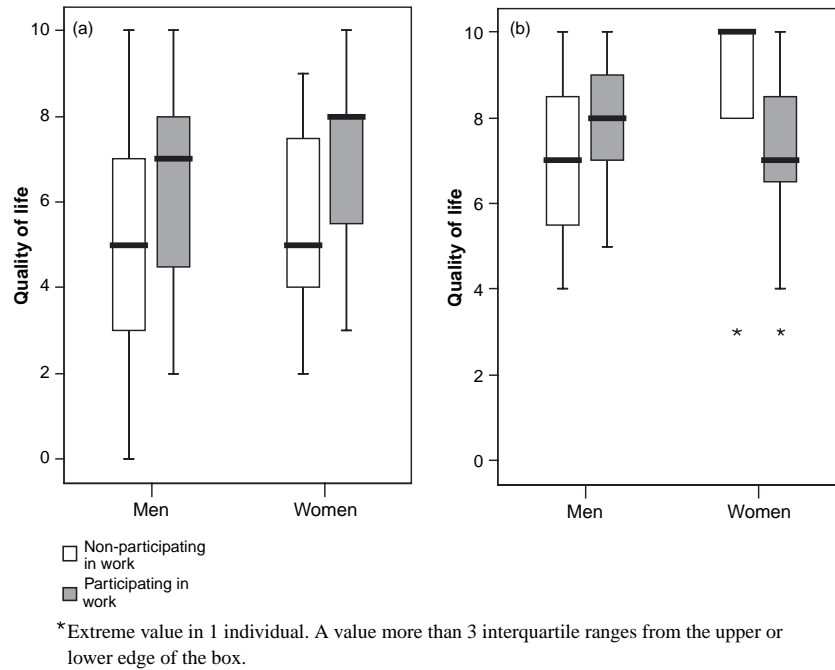


Fig. 1. Medians (bold lines) with lower and upper quartiles (lower and upper edge of boxes) and range (whiskers) for quality of life according to current employment status. (a) Traumatic spinal cord injury. (b) Meningomyelocele.

with meningomyelocele rated satisfaction with their current work situation as very or rather good. There was no significant association between current work participation and quality of life either in the men or in the women with meningomyelocele (Fig. 1b).

DISCUSSION

The overall employment rate in this study was 47% among persons with traumatic SCI and 40% among persons with meningomyelocele. The results are in line with those from a previous Swedish study by Levi et al. (27). They reported that 46% of their study population, consisting of persons with SCI living in Greater Stockholm area in Sweden, were gainfully employed. These figures are clearly lower than the overall employment rate of 73% in the general Swedish population aged 15–64 years in 2003 (28). On the other hand, the vocational outcome seems to be somewhat more optimistic than, for example, in the USA, where less than 30% of the 18–62-year-old persons with traumatic SCI were gainfully employed, or in the UK where only 26% of the persons with meningomyelocele aged 27–33 years were in open employment (9, 16). The wide variation in employment rates between different countries can at least partly be explained by differences in social support and insurance systems. However, differences in the length of rehabilitation, as well as differences in people’s attitudes to persons with functional impairments may also play a role.

Despite the fact that meningomyelocele is a congenital SCI, rehabilitation outcomes are seldom compared with those with traumatic SCI. This is probably due to the fact that 80% of

persons with meningomyelocele are born with hydrocephalus, which is often accompanied with mild cognitive impairment (29). On the other hand, recent studies have shown that traumatic SCI may be accompanied by traumatic brain injury even more often than we have thought (30). Another fundamental difference between the groups is that subjects with meningomyelocele are born with a disability and lack the experience of a “healthy” childhood. In Göteborg, Sweden, persons with traumatic SCI and persons with meningomyelocele are rehabilitated at different departments of Sahlgrenska University Hospital. The lack of difference in work participation rates between these 2 groups suggests that existing resources and possibilities are used effectively at both departments. One could argue that the relatively high employment rate in the meningomyelocele group is artificial, since the proportion of those whose employer received wage supplement from the government was higher in the meningomyelocele group than in the traumatic SCI group. We want to emphasize that to have this kind of support as a disabled person, one has to find a way to the labour market by attracting an employer. Furthermore, this kind of support covers only part of the employment costs and is time-limited. Therefore this support is different from sheltered work.

Men and women with traumatic SCI also seemed to differ from each other regarding the predictors of work participation. Age, age at injury, and neuropathic pain, for example, did not seem to affect work participation in the women with traumatic SCI. We do not know whether neuropathic pain not being a predictor is due to higher tolerance or better coping strategies among the women or something else. Previous studies have

shown that coping strategies differ between men and women, women using emotion-focused coping more frequently than men (31). However, the results of this study emphasize the importance of maintaining genus perspective in SCI rehabilitation and research.

The fact that neurological level or ambulatory status did not affect work participation in the subjects with traumatic SCI was somewhat surprising. A more detailed assessment of the degree of neurological impairment might have provided additional information, but was not available in our study. Among the persons with meningomyelocele use of a wheelchair for ambulation increased the risk of non-participation in work. In this patient group ambulatory status may more reflect the overall functional and cognitive capacity than in the traumatic SCI group. On the other hand, higher functional independence, assessed by the SRFM, predicted work participation in all subgroups. It is encouraging that in the traumatic SCI group the persons with limited ambulatory capacity seemed to have equal opportunities to participate in work. It is therefore worthwhile to rehabilitate these persons vocationally despite the neurological level of the injury. However, independence in daily activities is a factor that should be taken into consideration when considering possibilities of vocational rehabilitation. Based on the results of our study SRFM seems to be a useful tool in assessing SCI person's vocational capacity.

Previous studies in persons with traumatic SCI and meningomyelocele have shown that problems with bladder and bowel function are associated with work participation and quality of life (18, 20, 32, 33). Therefore, our results showing no association between urinary or faecal incontinence and work participation in any of the subgroups were unexpected. One explanation could be the duration of rehabilitation in Sweden, which is much longer than for example in the USA (34). During a longer rehabilitation period a person has more time to learn how to cope with the problem in everyday life. Improved incontinence aids could be another explanation for the differences in the results between our study and previous studies.

According to our clinical experience mental disorders, as well as alcohol and narcotic abuse are a frequent problem among persons with traumatic SCI, and may actually have predisposed the subjects to their injury. These disorders have rarely been taken into consideration in studies on vocational outcome. Our results showed that the presence of mental disorder is a strong risk factor for non-participation in work. There is a need for collaboration between specialists in the rehabilitation of SCI and specialists in psychiatric rehabilitation. The fact that we did not find any association between narcotic abuse and work participation may be due to selective non-response, i.e. the abusers replying less frequently to our questionnaire than the others, or denial of abuse by the respondents.

The association between the level of education and work participation in the traumatic SCI group was not as strong as previously reported (7, 9). This might be due to the relatively complex classification system of different educational levels in Sweden. Furthermore, the educational system has changed to

some extent during the last decades. On the other hand, in the meningomyelocele group, higher level of education was clearly associated with better vocational outcome. It was also quite encouraging to find out that vocational rehabilitation improved work participation at least in the men with SCI.

In our study 6% of persons with traumatic SCI and 8% of persons with meningomyelocele reported that they had been bullied at work. These numbers are at the same level as those in the normal Swedish population. According to the Work Environment Survey carried out by Statistics Sweden in 2001 9% men and 9% women had been bullied by supervisors or fellow employees (35). We did not find any reports concerning bullying in traumatic SCI, but according to one study in subjects with meningomyelocele employers showed unfavourable attitudes towards the disabled in 9–10% of cases and 2% of the responders reported having been encountered with unfavourable attitudes from their colleagues (19, 20).

Nearly 80% in both patient groups rated satisfaction with their current work situation as very good or rather good. This is at the same level as in the general Swedish population, in which the corresponding proportion has been about 75% (36). The similarity in the level of satisfaction in different life domains between persons with meningomyelocele and an average population is in line with previous studies (37). Our results support the previous findings according to which work participation is associated with better quality of life in persons with SCI (7, 8). However, the cross-sectional design of our study does not allow conclusions regarding causality.

One of the weaknesses of this study was the relatively low response rate, which may be due to an extensive questionnaire. Although our analyses showed that our study groups were well representative of the total study populations with regard to gender and neurological level, there are sources of potential bias. There is a possibility that those with better functional capacity and better vocational outcome responded more often than those with more severe functional impairments or the unemployed. The fact that we were limited to self-reported data indicates the need for caution in interpreting the results especially as regards the medical characteristics.

In terms of International Classification of Functioning, Disability and Health (ICF) our main focus was to study effect of impairments in body structure and functions on work participation (38). We also studied activities and participation by assessing mobility in terms of ambulatory capacity and independence in self-care with the SRFM. In multivariate modelling higher independence in self-care turned out to be one of the primary predictors of work participation. More detailed information about associations between functioning and work participation could have been obtained by including also environmental factors, which, however, were not in the scope of this study.

Gainful employment is usually considered as one of the most important goals of rehabilitation. Considering the difference between employment rates in the general population and persons with SCI, one can say that there is still space for

improvement. On the other hand, gainful employment is not the only goal for rehabilitation. Independence in daily activities and quality of life are other important aspects of rehabilitation. Therefore, it is a matter of opinion, if a work participation rate in persons with severe functional impairments of two-thirds that in the healthy population (about 50% against 75%) is the considered attainment of the goal. However, active rehabilitation and continuous support of persons with SCI towards work participation is worthwhile, since employment may improve quality of life.

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