J Rehabil Med 2021; 53: jrm00217

ORIGINAL REPORT

# PARTICIPATION AND QUALITY OF LIFE IN PERSONS LIVING WITH SPINAL CORD INJURY IN NORWAY

Annette HALVORSEN, MD[1,2,3], Kristine PAPE, PhD[3], Marcel W. M. POST, PhD[4,5], Fin BIERING-SØRENSEN, PhD[6], Steinar MIKALSEN[7], Anders Nupen HANSEN[8] and Aslak STEINSBEKK, PhD[1,3]

*From the [1]Clinic of Physical Medicine and Rehabilitation, Department of Spinal Cord Injuries, [2]Department of Medical Quality Registries, St Olavs Hospital, Trondheim University Hospital, [3]Department of Public Health and Nursing, Norwegian University of Science and Technology, Trondheim, Norway, [4]Center of Excellence for Rehabilitation Medicine, Brain Centre Rudolf Magnus, University Medical Centre Utrecht, University Utrecht and De Hoogstraat Rehabilitation, Utrecht, [5]University of Groningen, University Medical Centre Groningen, Centre for Rehabilitation, Groningen, The Netherlands, [6]Department for Spinal Cord Injuries, Copenhagen University Hospital, Rigshospitalet, and Institute for Clinical Medicine, University of Copenhagen, Denmark, [7]User Representative, Skogn and [8]User Representative, Kongsvinger, Norway*

***Objectives:*** **To describe the association between sociodemographic and spinal cord injury characteristics, of people living with spinal cord injury, and participation and quality of life, and to study the association between participation and quality of life in this group of people.**

***Design:*** **Persons registered in the Norwegian Spinal Cord Injury Registry after post-acute rehabilitation between 2011 and 2017 were invited to participate in a survey in 2019 when they were in a community setting.**

***Subjects:*** **A total of 339 people living with spinal cord injury.**

***Methods:*** **The Frequency scale and Restrictions scale of the Utrecht Scale for Evaluation of Rehabilitation-Participation were used to measure participation. Quality of life was measured as life satisfaction with the World Health Organization Quality of life assessment (WHOQoL-5) and mental health was measured using the Mental Health subscale (MHI-5).**

***Results:*** **Overall, sociodemographic characteristics were more prominently associated with quality of life and participation than were spinal cord injury characteristics. Currently working as main activity and having a family income in the highest quartile were associated with higher scores on all 4 measures of participation and quality of life. There was a strong gradient between higher level of participation (frequency and restrictions) and better quality of life.**

***Conclusion:*** **Participation was strongly associated with life satisfaction and mental health in people living with spinal cord injury. This indicates that participation issues should be given greater priority during post-acute rehabilitation, follow-up and subsequent care efforts provided in the community.**

*Key words:* spinal cord injuries; participation; quality of life; Norway.

Accepted Jun 21, 2021; Epub ahead of print Jun 29, 2021

J Rehabil Med 2021; 53: jrm00217

Correspondence address: Annette Halvorsen, Clinic of Physical Medicine and Rehabilitation, Department of Spinal Cord Injuries, St Olavs hospital, Trondheim University Hospital, Trondheim, Norway. E-mail: Annette.Halvorsen@stolav.no

## LAY ABSTRACT

Having paid work, leisure-time activities and good relationships with other people is important for one's quality of life. For people living with spinal cord injury, it may be more difficult to participate in such activities than it is for people without health problems. A survey on participation problems was carried out among Norwegians living with spinal cord injury. Sociodemographic factors, such as family income and education, were found to have a greater impact on quality of life and participation, than the severity of the injury itself. Participation was strongly associated with life satisfaction and mental health. This indicates that participation issues should be given greater priority.

Participation provides opportunities for the fulfilment of basic human needs and can be an important determinant of quality of life (QoL) (1). Persons living with spinal cord injury (SCI) may, however, experience restrictions or barriers to participation in different domains, including employment or social-recreational activities (2). Research on issues related to participation problems among persons with SCI is, however, limited. In a critical systematic review on social and community participation following SCI (3), the authors emphasized that the samples in the reviewed studies were relatively small, that the instruments used were often developed before the introduction of the International Classification of Functioning, Disability and Health (ICF), and that the use of the term "participation" varied. In addition, knowledge about the impact of injury characteristics on participation is underdeveloped (2). Furthermore, limited attention has been given in the literature to how clinical practice can be adapted to improve participation in persons with SCI. To do so, more knowledge of factors influencing participation is needed.

In the ICF, "participation" refers to the involvement of an individual in a life situation and represents the social perspective on functioning (4). To measure participation, it has been recommended to measure participation both as the so-called objective state and subjective experience (5). Objective participation can be measured as self-reported frequencies of behaviour, while subjective participation concerns self-reported experienced restrictions in participation in society. It has been commented that the ICF definition of participation does not adequately capture this (6).

doi: 10.2340/16501977-2858

QoL is a broad concept, and has been defined by the World Health Organization (WHO) as the individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It can be operationalized to distinguish between the cognitive component that refers to life satisfaction and the emotional component that refers to a person's affect or mental health (8).

People with SCI experience lower QoL, as shown by higher levels of distress, worse mental health and lower levels of life satisfaction compared with the general population (9, 10). Studies have indicated that decreased mobility (11, 12), having secondary impairments (11, 12), pain (11, 13) and unemployment (14) are associated with lower QoL. Increased QoL has been associated with psychosocial characteristics, such as higher self-efficacy (15), good social skills (15), more social support (9) and a feeling of acceptance (16). The associations between QoL and age, sex, education, injury level and injury duration are inconsistent (9, 12, 17). However, there is variation in study design, inclusion criteria, and measure instruments, and cohort studies with a representative sample and sufficient sample size have been requested (9).

Studies exploring the association between participation and QoL indicate that participation is related to higher life satisfaction (1, 18). However, little is known about risk groups for poor participation and poor QoL and knowledge about risk profiles can help in intervention planning.

The objectives of this study were therefore to assess participation and QoL with validated generic measurement instruments in a representative sample. Specific aims were: (*i*) to describe the association between sociodemographic and SCI characteristics with participation and QoL; (*ii*) to detect groups at risk for low participation/poor QoL; and (*iii*) to study the association between participation and QoL.

## METHODS

### *Design*

Persons registered in the Norwegian SCI Registry (NorSCIR) between 2011 and 2017 (first rehabilitation setting, baseline) were identified, and followed up in a survey performed in 2019 (community setting, follow-up). NorSCIR is a national medical quality registry for SCI care. All patients with traumatic or non-traumatic SCI admitted for first rehabilitation to 1 of the 3 Norwegian specialized SCI departments and who give their consent are included in the registry. Annual analyses revealed 90% completeness in the NorSCIR. Information about NorSCIR and all annual reports are available on the internet (www.norscir.no). Ethical approval for this study was obtained from regional committees for medical and health research ethics (2018/294/REK midt).

### *Participants*

Eligible for this study were persons aged 16 years or older (thus 18 years and over at the time of survey (follow-up)), registered for the first time in the NorSCIR between 1 January 2011 and 31 December 2017 and registered as alive and living in Norway, based on the linkage to the national register at the time of the survey (follow-up). Information from non-responders was used to perform a non-responder analysis.

### *Procedures*

A digital invitation was sent to all eligible persons. Those not answering the digital questionnaire were invited by post. Information about the study was published on the Facebook page and in the magazine of members of the Norwegian SCI consumer organization/patient organization "LARS" (available from https://www.lars.no/ )to create awareness among those who were invited. Up to 2 reminders were sent to non-responders.

### *Measures*

Variables measured at follow-up were participation and QoL and some sociodemographic variables (education, income and living situation). Variables regarding injury characteristics, time since discharge, age and sex, were collected from the NorSCIR (baseline).

*Participation.* Participation was measured with the Frequency scale and the Restrictions scale of the Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation) (19). The USER-Participation instrument was developed based on the ICF to assess objective and subjective participation. The psychometric properties of the USER-Participation have been studied (20). The translation of the USER-Participation from English to Norwegian was performed according the guidelines from the WHO for the process of translation and adaptation of instruments. The Satisfaction scale of the USER-Participation was not included in this study, due to conceptual overlap with the World Health Organization Quality of life assessment (WHOQoL) instrument.

The Frequency scale measures objective participation and consists of 4 items on vocational activities and 7 items on leisure and social activities. The 4 items on vocational activities address the number of hours spent per week and are scored on a 6-point ordinal scale from 0 (not at all) to 5 (36 h per week or more). The 7 items on leisure and social activities address the frequency in the last 4 weeks scoring from 0 (never) to 5 (19 times or more). The Restrictions scale consists of 11 items that address activities that may be restricted by their health condition. The perceived difficulty in performing the activity is rated on a 4-point scale, ranging from 0 (not possible at all) to 3 (without difficulty). If an item is not relevant to the person, or the restrictions are not related to the person's health status, the option "not applicable" is available. For each scale the sum score based on all applicable items (maximum 11 items) was converted to a 0–100 scale, with higher scores indicating better participation (more time spent/higher frequency, fewer restrictions).

The continuous scale scores for USER-Participation frequencies and restriction were divided into quartiles.

*Quality of life.* The cognitive component of QoL was measured as life satisfaction with 5 satisfaction items from the WHOQoL-5 (21) and the emotional component of QoL with the Mental Health subscale (MHI-5) (22).

The WHOQoL-5 is a selection of 5 satisfaction items out of the abbreviated version of the WHOQOL-100 (the WHOQOL-BREF). The WHOQOL-BREF is available in 85 languages, including Norwegian, and is specifically developed for cross-cultural use. The WHOQOoL-5 has previously showed good internal consistency reliability and cross-cultural validity in persons with SCI (21). The 5 items cover satisfaction with overall QoL, health, daily activities, relationships, and living conditions. Response options range from 1 (very poor/very dissatisfied) to 5 (very good/very satisfied) for each item, yielding a total score between 5 (very dissatisfied) and 25 (very satisfied).

The MHI-5 refers to the Mental Health subscale of the Medical Outcomes Study Short Form Health Survey (SF-36, available in Norwegian), and consists of 5 items of emotional status concerning nervousness, sadness, peacefulness, mood, and happiness. The validity and reliability of the MHI-5 in persons with SCI was good in previous studies (22). Respondents rated the frequency of each item during the previous 4 weeks on a 5-point scale. The scale scores were converted to a total score between 0 (lowest mental health) and 100 (highest mental health).

The self-reported QoL (International SCI QoL-Basic Data Set (23)) at discharge from the initial post-acute rehabilitation period was used to compare the participants and non-participants at baseline. It consists of 3 variables rated on a scale ranging from 0 (completely dissatisfied) to 10 (completely satisfied): satisfaction with general QoL, satisfaction with physical health, and satisfaction with psychological health.

*Sociodemographic characteristics.* Sociodemographic information included sex, age, level of education (primary, secondary or higher), family income (under 250,000, 250,000–500,000, 500,000–750,000, 750,000–1,000,000 and above 1,000,000 Norwegian kroner per year), main activity (currently working, retirement age, social welfare recipient, student, or other) and living situation (alone or together) in categories. The categorization of age groups (–29, 30–59 and 60+ years) followed the newest recommendations of the International SCI Core Data Set version 2.0. The responders were asked to indicate which response option was most appropriate for their situation.

*Injury characteristics.* Clinical injury characteristics were defined according to the International SCI Core Data Set version 1.1 (25), as used in NorSCIR. Study variables included dates of admission and discharge from initial acute and rehabilitation care, cause of injury and neurological status at admission and discharge. Neurological status is registered with the sensory and motor level on each side of the body and the American Spinal Injury Association Impairment Scale (AIS) in accordance with the International Standards for Neurological Classification of SCI (26). Prompted by the distribution of neurological status at discharge, we decided to use 4 categories: tetraplegia (C1–C8) AIS A, B or C; tetraplegia (C1–C8) AIS D, E; Paraplegia (T1–S5) AIS A,B or C; Paraplegia (T1–S5) AIS D,E. In cases of missing neurological status at discharge ($n$=61), this was replaced with the classification at admission ($n$=50) or based on the self-reported level and completeness of the SCI in combination with the mobility for moderate distances from the Spinal Cord Independence Measure – Self Report ($n$=7, e.g. incomplete paraplegia and walking without walking aids was categorized as ”Paraplegia (T1–S5) AIS D,E”). The impairment groups (neurological level and AIS) are used to describe the severity of injury, For example, have those grouped in ”Tetraplegia A,B,C” a more severe injury compared with those grouped in ”Paraplegia D,E”. Time since discharge was calculated as the number of days between the date of discharge from the SCI department and the date of answering the survey. Thereafter, this number was dichotomized into ”4 years or less since discharge” or ”more than 4 years since discharge”.

### *Analysis*

The analyses mainly followed the recommendations from the International Spinal Cord Injury Core Data Set; continuous variables to be expressed as both mean with standard deviation and median with range, and categorical variables to be presented as number of cases and percentages.

Comparisons of baseline characteristics between participants and non-participants were done using *t*-tests for continuous and $\chi^2$ for categorical variables.

In separate analyses for each dimension of QoL (life satisfaction and mental health) and participation (frequencies and restrictions), we assessed both the bivariable (1-way analysis of variance (ANOVA)) and multivariable (regression) associations with injury and sociodemographic characteristics. The regression analyses were adjusted for sex, age group, education level, time since discharge group, cause of injury and impairment group (neurological level and AIS) to control for confounding variables. Since the same results were found in both the bi- and multi-variable analyses, only the bi-variable analyses are presented in the results section, as these give the actual observed data, which are easier to relate to clinical practice. The multivariable analyses are presented as supplementary material only (Table SV[1]).

The relationship between level of participation (quartiles of Frequency and Restriction scale scores) and QoL was analysed using linear regression analyses, with adjustment for sex, age group, education level, time since discharge group, cause of injury and impairment group.

## RESULTS

Of the 651 individuals invited to complete the follow-up survey, 339 participated (52%) (Fig. 1). Participants were, on average, older than non-participants. Otherwise, there was little difference between participants and non-participants (Table I).

The mean age of the participants at the time of the survey was 58 years (median 61 years, range 18–91 years). The mean time since discharge was 4.4 years (range 0.9–8.7 years). One-quarter were female, 60% had a traumatic SCI, 40% tetraplegia, and 67% of all participants were classified with AIS D-E. Two out of 3 participants lived together with someone, and slightly more than 55% of respondents had an annual family income above NOK 500,000 (EUR 46,670/

---

[1] https://doi.org/10.2340/16501977-2858

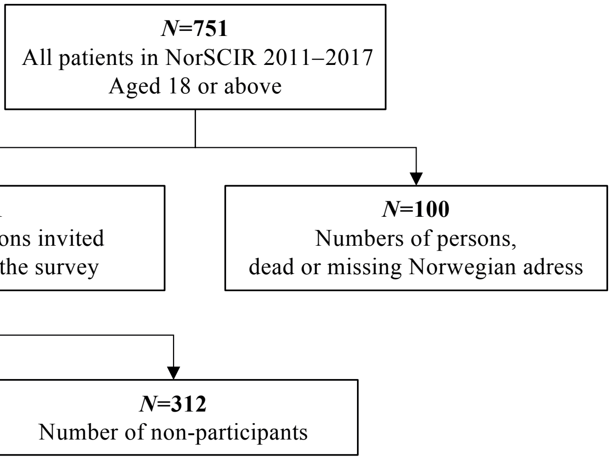

**Fig. 1.** Flow-chart of study participants.

USD 54,132). Most participants reported secondary education (45%), or higher (40%) (Table II).

The mean Participation Frequency score was 30.7 (SD 11.9), and for Participation Restrictions 70.3 (SD 20.5) both on a 0–100 scale where higher scores indicated better participation (higher frequency, fewer restrictions). The subscales for the Frequency score showed a mean score 16.5 (SD 13.2) for the vocational scale and 44.6 (SD 16.7) for the leisure and social activity scale, both on a 0–100 scale (details in Table SI[1] and Table SII1).

**Table I**. Descriptive characteristics of participants ($n = 339$) and non-participants ($n = 312$)

| Characteristics | Participants | Non-participants |
|---|---|---|
| Demographic variables | | |
| Mean age at baseline, years, mean (SD) | 53.2 (16.1)[a] | 46.9 (18.6)[a] |
| Age groups at baseline, *n* (%) | [a] | [a] |
| 16–29 years | 40 (12) | 74 (24) |
| 30–59 years | 156 (46) | 143 (46) |
| 60 years | 143 (42) | 95 (30) |
| Sex, *n* (%) | | |
| Male | 243 (72) | 225 (72) |
| Female | 96 (28) | 87 (28) |
| SCI Characteristics | | |
| Cause of injury, *n* (%) | | |
| Traumatic | 203 (60) | 206 (66) |
| Non-traumatic | 136 (40) | 106 (34) |
| Impairment groups (Level and AIS), *n* (%) | | |
| Tetraplegia, AIS A-C | 34 (10) | 46 (15) |
| Tetraplegia, AIS D-E | 102 (30) | 81 (26) |
| Paraplegia, AIS A-C | 76 (22) | 63 (20) |
| Paraplegia, AIS D-E | 123 (36) | 110 (35) |
| Unknown or not applicable | 4 (1) | 12 (4) |
| Mean time since discharge, mean (SD) | 4.4 (1.9) | 4.4 (2.0) |
| SCI-QoL BDS at baseline (range 0–10) (from NorSCIR)[b] | | |
| Mean satisfaction with general quality of life, (SD) | 6.7 (2.3) | 6.3 (2.4) |
| Mean satisfaction with physical health, (SD) | 6.1 (2.4) | 5.7 (2.5) |
| Mean satisfaction with psychological health, (SD) | 7.1 (2.4) | 6.6 (2.7) |

[a] *p*-value $< 0.05$ from *t*-tests for continuous and $\chi^2$ for categorical. [b] $n = 213$ participants and $n = 173$ non-participants.
SCI: spinal cord injury; AIS: American Spinal Injury Association Impairment Scale; QoL: quality of life; BDS: basic data set; NorSCIR: Norwegian SCI Registry.

For life satisfaction, the mean WHO QoL-5 score was 16.9 (SD 3.7) on a 5–25 scale. One in 5 (18%) rated their QoL as poor or very poor.

For mental health, the mean MHI-5 score was 71.9 (SD 19.5) on a 0–100 scale (details in Table SIII[1] and Table SIV[1]).

Results from the bivariate analysis are shown in Table II. Main daily activity and family income were associated with all participation and QoL indicators. For both participation indicators (frequency and restrictions), significant and graded associations with age and education were apparent. Participants living together with someone reported higher QoL, in general, both regarding life satisfaction and mental health. As explained in the methods section, the multivariable analyses gave the same results as the bi-variable analyses and are presented as supplementary material only (Table SV[1]).

For both indicators of QoL, the reported level differed according to age group. The older age group reported higher mental health, while the youngest age group reported higher life satisfaction.

For both indicators of QoL, the reported level differed according to age group. The older age group reported higher mental health, while the youngest age group reported higher life satisfaction.

For both life satisfaction and mental health, there was a clear gradient with level of participation in both the unadjusted and adjusted models (Table III and Fig. 2): scoring higher on both Frequency and Restrictions was associated with improved life satisfaction and mental health.

**Table II.** Description of participants, and score on self-reported participation and quality of life according to patient characteristics (*n* = 339[a])

| Variable | *n* (%) | USER-P freq (Range 0–100) Mean (95% CI) | USER-P restr (Range 0–100) Mean (95% CI) | WHO QoL-5 (Range 5–25) Mean (95% CI) | MHI-5 (Range 0–100) Mean (95% CI) |
|---|---|---|---|---|---|
| Total mean score, mean (SD) | 339 (100) | 30.7 (11.9) | 70.3 (20.5) | 16.9 (3.7) | 71.9 (19.5) |
| Demographic variables | | | | | |
| Age-groups at follow-up | | b | b | | b |
| 18 to 29 years | 29 (9) | 36.0 (31.9–40.1) | 75.8 (68.5–83.1) | 17.5 (16.1–18.8) | 66.7 (59.7–73.7) |
| 30 to 59 years | 130 (38) | 34.6 (32.6–36.6) | 75.2 (71.7–78.6) | 16.6 (16.0–17.3) | 67.7 (64.4–71.0) |
| 60+ years | 180 (53) | 26.9 (25.2–28.6) | 65.9 (63.0–68.9) | 17.1 (16.5–17.6) | 75.7 (72.9–78.5) |
| Sex | | | b | | |
| Male | 243 (72) | 30.8 (29.3–32.4) | 72.0 (69.4–74.6) | 16.8 (16.3–17.2) | 72.4 (69.9–74.8) |
| Female | 96 (28) | 30.4 (27.9–32.8) | 66.1 (62.0–70.2) | 17.4 (16.7–18.2) | 70.7 (66.8–74.6) |
| Level of education | | b | b | b | |
| Primary | 50 (15) | 22.9 (19.7–16.0) | 59.5 (54.0–65.0) | 15.7 (14.7–16.8) | 70.8 (65.4–76.2) |
| Secondary | 151 (45) | 30.1 (28.2–31.9) | 69.4 (66.2–72.5) | 16.9 (16.4–17.5) | 72.2 (69.1–75.3) |
| Higher | 132 (40) | 34.8 (32.8–36.7) | 75.9 (72.5–79.3) | 17.4 (16.8–18.0) | 72.7 (69.4–76.1) |
| Spinal cord injury characteristics | | | | | |
| Time since discharge | | | | | |
| 4 years or less | 155 (46) | 31.3 (29.3–33.2) | 69.5 (66.2–72.7) | 16.9 (16.3–17.5) | 72.0 (69.0–75.1) |
| More than 4 years | 184 (54) | 30.2 (28.4–32.0) | 71.1 (68.1–74.0) | 16.9 (16.4–17.5) | 71.8 (68.9–74.6) |
| Cause of injury | | | | | |
| Traumatic | 203 (60) | 31.2 (29.5–32.8) | 70.2 (67.4–73.1) | 17.0 (16.5–17.5) | 70.7 (68.0–73.4) |
| Non-traumatic | 136 (40) | 30.0 (27.9–32.0) | 70.5 (67.0–73.9) | 16.8 (16.2–17.5) | 73.6 (70.3–76.9) |
| Impairment groups (level and AIS) | | | b | | |
| Tetraplegia A,B,C | 34 (10) | 28.0 (23.8–32.1) | 51.7 (45.0–58.3) | 16.6 (15.3–17.8) | 73.5 (66.9–80.1) |
| Tetraplegia D,E | 102 (30) | 29.8 (27.4–32.1) | 72.2 (68.4–76.0) | 16.5 (15.8–17.3) | 71.9 (68.0–75.7) |
| Paraplegia A,B,C | 76 (23) | 31.6 (28.8–34.3) | 70.4 (66.0–74.8) | 17.4 (16.6–18.3) | 72.1 (67.7–76.5) |
| Paraplegia D,E | 123 (37) | 31.7 (29.5–33.9) | 73.7 (70.2–77.1) | 17.0 (16.4–17.7) | 71.0 (67.5–74.5) |
| Social variables | | | | | |
| Main daily activity | | b | b | b | b |
| Currently working | 75 (23) | 39.6 (37.2–42.1) | 81.9 (77.5–86.3) | 18.3 (17.5–19.1) | 73.3 (68.9–77.7) |
| Retirement age | 113 (34) | 26.0 (24.0–18.0) | 65.6 (62.0–69.2) | 16.9 (16.3–17.6) | 76.1 (72.5–79.7) |
| Social welfare recipient | 120 (36) | 28.3 (26.4–30.3) | 66.3 (62.9–69.8) | 16.1 (15.5–16.8) | 68.8 (65.3–72.3) |
| Students | 11 (3) | 42.0 (35.7–48.3) | 84.4 (72.9–95.9) | 17.0 (14.8–19.2) | 69.1 (57.6–80.6) |
| Other (homemaker, jobseeker) | 14 (4) | 31.0 (25.5–36.6) | 72.5 (62.3–82.7) | 16.4 (14.4–18.3) | 62.9 (52.7–73.0) |
| Living situation | | | | b | b |
| Alone | 104 (31) | 29.4 (27.1–31.7) | 68.3 (64.3–72.2) | 16.3 (15.6–17.0) | 66.2 (62.5–69.9) |
| Together | 227 (69) | 31.3 (29.7–32.8) | 71.0 (68.3–73.6) | 17.2 (16.7–17.7) | 74.4 (71.9–76.9) |
| Family income (Norwegian kroner per year) | | b | b | b | b |
| Below 250.000 | 29 (9) | 24.1 (19.9–28.3) | 63.2 (56.1–70.3) | 15.6 (14.2–16.9) | 57.1 (50.2–63.9) |
| 250.000 to 500000 | 107 (35) | 28.5 (26.4–30.7) | 67.3 (63.6–71.0) | 16.6 (15.9–17.3) | 72.2 (68.6–75.8) |
| 500.000 to 750.000 | 76 (25) | 30.3 (27.8–32.8) | 72.1 (67.8–76.5) | 16.8 (16.0–17.6) | 73.4 (69.1–77.6) |
| 750.000 to 1 million | 52 (17) | 33.6 (30.5–36.7) | 73.4 (68.1–78.6) | 16.8 (15.8–17.8) | 71.4 (66.3–76.6) |
| Above 1 million | 44 (14) | 38.0 (34.7–41.4) | 81.2 (75.5–87.0) | 19.1 (18.0–10.2) | 79.4 (73.9–85.0) |

[a]*n* vary from 300 to 339 for different variable due to missing or preferring not to answer. [b]*p*-value < 0.05 from Oneway Anova
USER-P freq: Frequency scale of the Utrecht Scale for Evaluation of Rehabilitation-Participation; USER-P restr: Restrictions scale of the Utrecht Scale for Evaluation of Rehabilitation-Participation; WHOQoL-5: World Health Organization Quality of life assessment; MHI-5: Mental Health subscale of the Medical Outcomes Study Short Form Health Survey; AIS: American Spinal Injury Association Impairment Scale; SD: standard deviation.

**Table III.** Unadjusted and adjusted association between Participation (USER-P Frequency, USER-P Restrictions) and Life satisfaction and Participation and Mental health in quartiles (Q1–Q4) where higher quartile is more frequency and less restriction in participation (*n* = 329)

| | Life satisfaction (WHOQoL-5) Mean (95%CI) | | Mental health (MHI-5) Mean (95%CI) | |
|---|---|---|---|---|
| Variables (Quartile, Score range) | Unadjusted model | Adjusted model[a] | Unadjusted model | Adjusted model[a] |
| Participation Frequency | *p* < 0.001 | | *p*=0.0029 | |
| Quartile 1, 2.9–22.5 | 15.0 (14.2–15.8) | 14.9 (14.1–15.7) | 66.4 (62.3–70.6) | 62.9 (58.7–67.1) |
| Quartile 2, 22.9–30.7 | 16.7 (15.9–17.5) | 16.7 (15.9–17.4)[b] | 71.8 (67.8–75.8) | 71.1 (67.2–74.9)[b] |
| Quartile 3, 31.1–37.9 | 17.4 (16.6–18.1) | 17.4 (16.6–18.1)[b] | 72.8 (68.7–76.9) | 73.8 (69.9–77.7)[b] |
| Quartile 4, 38.2–62.5 | 18.6 (17.8–19.3) | 18.7 (18.0–19.5)[b] | 77.5 (73.5–81.5) | 80.6 (76.6–84.6)[b] |
| Participation Restrictions | *p* < 0.001 | | *p* < 0.001 | |
| Quartile 1, 0–57.1 | 15.3 (14.6–16.0) | 14.8 (14.1–15.6) | 66.9 (62.9–71.0) | 63.4 (59.2–67.5) |
| Quartile 2, 57.6–70.8 | 15.8 (15.1–16.6) | 15.9 (15.2–16.6)[b] | 68.0 (63.8–72.2) | 67.5 (63.4–71.6) |
| Quartile 3, 72.7–83.3 | 16.6 (15.9–17.3) | 16.6 (15.9–17.3)[b] | 72.5 (68.5–76.5) | 73.3 (69.4–77.1)[b] |
| Quartile 4, 84.8–100 | 19.8 (19.1–20.5) | 20.2 (19.5–20.9)[b] | 80.2 (76.3–84.1)b | 83.3 (79.3–87.2)[b] |

[a]Adjusted for sex, age group, education, time since discharge group, cause of injury group, impairment group (neurological level and AIS, American Spinal Injury Association Impairment Scale). [b]*p*-value< 0.05 from linear regression.
Participation Frequency: Frequency scale of the Utrecht Scale for Evaluation of Rehabilitation-Participation; Participation Restrictions: Restrictions scale of the Utrecht Scale for Evaluation of Rehabilitation-Participation; WHOQoL-5: World Health Organization Quality of life assessment; MHI-5: Mental Health subscale of the Medical Outcomes Study Short Form Health Survey.

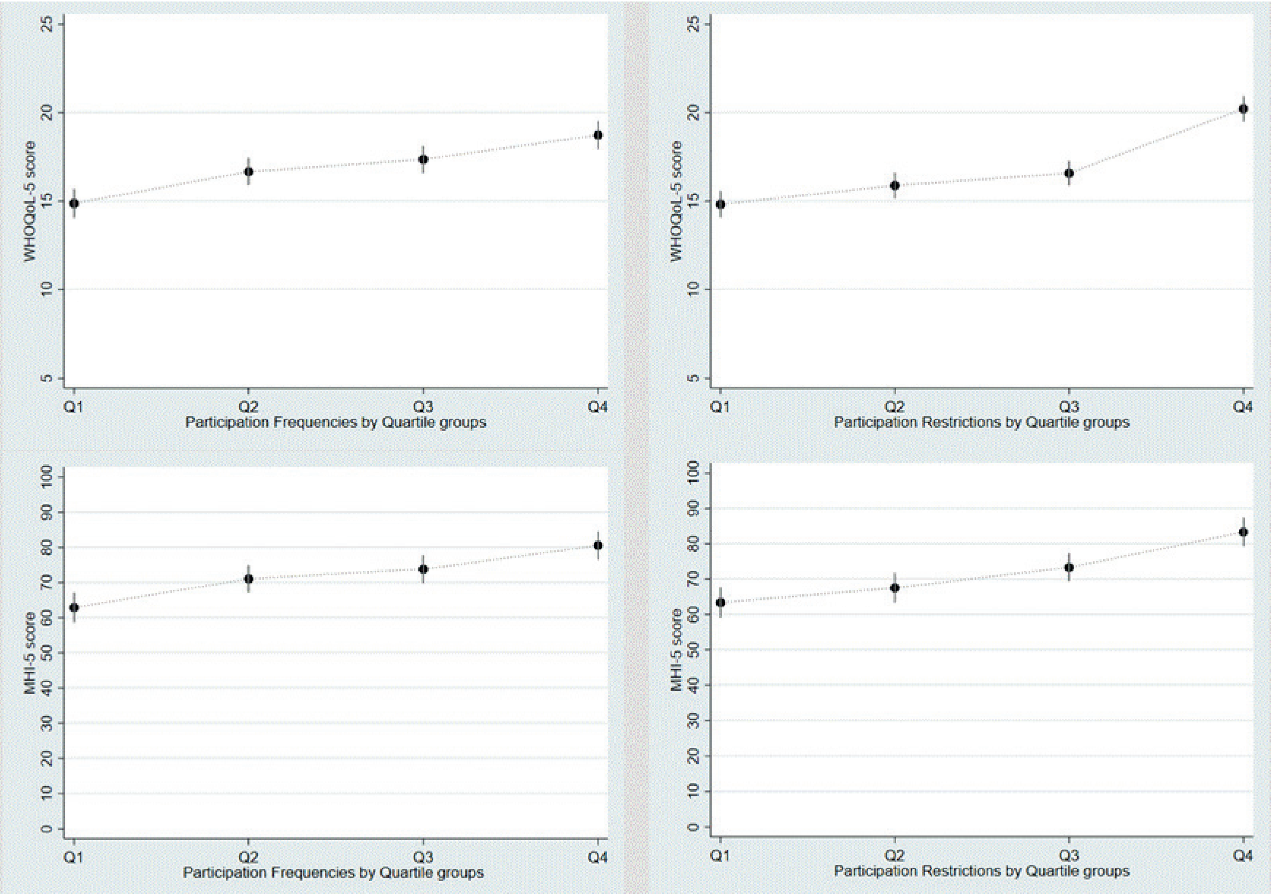

**Fig. 2.** Adjusted association between participation (frequencies and restrictions) and quality of life (life satisfaction and mental health).

## DISCUSSION

Overall, sociodemographic characteristics were more prominently associated with QoL and participation than were SCI characteristics. In particular, participants who reported to be currently working as their main activity and had a high family income had higher scores on all 4 measures of participation and QoL than those who were not working and had lower income. There was a strong gradient between participation (frequency and restrictions) and QoL (life satisfaction and mental health).

The levels of participation and QoL found in this study are in line with other SCI studies (20, 21, 29). A strong association between participation and quality of life was found, which is known from the SCI population (8), and from other fields (30). Thus, participation in society is important for life satisfaction and mental health and points to the importance of support to persons with SCI in creating opportunities to participate, e.g. in work life, physical activity and contributing to leisure activities. To achieve this, participation in society could be more highly prioritized during post-acute rehabilitation and used as a measure of effectiveness and efficiency of SCI rehabilitation

Except for severity of injury and restrictions in participation, there were no strong associations between injury characteristics recorded by the hospital (i.e. not self-reported) after injury and self-reported life satisfaction and mental health in the survey 1–8 years after injury. This is in line with other studies, which concluded that differences in life satisfaction and mental health are not well predicted by the severity of the injury (neurological level and completeness) (9, 17, 31, 32).

In contrast, there are indications that sociodemographic factors are more important for participation and QoL in the years after the injury. This points to modifiable social factors, such as employment (for those of working age as an important target during primary rehabilitation and later). Furthermore, healthcare professionals should be aware of the impact of age on life satisfaction, mental health and participation opportunities.

The associations found between currently working as main activity with both better participation and higher QoL are known from other studies (14). These studies show that employment ensures enhanced self-esteem, social relationships and economic self-efficiency, and work participation is therefore an important factor both for the person with SCI and for society. However, a large international study among people with SCI of working age showed that employment rates among participants with SCI were substantially lower than in the general population (33). That staff in vocational rehabilitation in many countries lack competencies in this area (34), further points to the need to focus on (work) participation during primary rehabilitation.

The opportunity to work is related to type of work, which, in turn, is related to level of education (34). It is known that level of education is associated with higher levels of quality of life and participation (35). In this study, both currently working and higher level of education were independently associated with life satisfaction and the 2 dimensions of participation, also after adjustment for injury characteristics and other sociodemographic factors (data shown in Table SV[1]). However, associations between educational level and mental health were less prominent, and findings from other related studies show conflicting results (27, 29). Nevertheless, the positive effect of educational attainment on QoL is very convincing (36). Planting the seed of the positive effect of higher education during primary rehabilitation to encourage, especially younger persons with a new SCI, to return to school and further education is thus justified.

Another aspect is the impact of the living situation of persons with SCI. Those living together with another person (adult or child), reported better life satisfaction and mental health, compared with those living alone. Living together is not the same as being married, but studies on the relationship between marital status and QoL has shown mixed results (12). Results from a 22-country study on SCI persons on the relationship of living situation/partnership status and mental health showed mixed associations, by the authors explained by the quality of the relationships, which is decisive for mental health and not solely the fact that there are others in the household or that one has a partner (37). Lower scores across the participation scales were associated with not having a partner also in another study (35). As expected, persons living alone reported lower family income (and own income, data not shown) compared with those living together. Higher family income was strongly associated with better QoL and participation, similar to findings in the Swiss SCI population (38). Norway and Switzerland are quite similar countries, both wealthy with highly developed healthcare systems and extended social security policies. The observed inequalities could therefore be even more pronounced in less wealthy countries.

### Study strengths and limitations

The main strength of this study is the linkage between patient data from a national medical SCI quality registry and survey data. The NorSCIR includes 90% of all patients admitted for primary rehabilitation to 1 of the 3 specialized SCI departments (located in Bergen, Trondheim and Oslo). A small number of patients may be admitted to other departments or discharged home, and are therefore not captured in the registry; for example, those with very limited sequelae.

Another strength is the comprehensive approach, by applying a broader perspective of participation than employment alone, measurement of both objective and subjective participation, and measurement of both life satisfaction and mental health. The final strength well worth mentioning is the involvement of user representatives as members of our research team. They used their personal experience to provide input to all steps from the study design to reporting the results, ensuring that this research is person-centred.

There are some noteworthy limitations. First, the observational study design must be considered when interpreting the results. Notably, conclusions on causal associations cannot be made. Secondly, the fact that half of the invited persons did not participate in the survey, may cause selection bias. Baseline characteristics for the non-responders showed only minor differences compared with the responders, and thereby little reason to believe that the relationships assessed in the study would differ for non-participants. This also strengthens the external validity, and the findings are likely to be generalizable to other developed countries with a similar highly developed healthcare system with specialized SCI units and extended social security policies. Thirdly, no information about household composition was available and we were not able to calculate equivalent household income as recommended by the Organisation for Economic Co-operation and Development (OECD) guidelines. The levels of family income and education among the participants were relatively high, although quite similar to the Norwegian population, where in 2019 the median income after tax for all households was 540,300 NOK (39) and 34.6% of Norwegians had achieved an upper secondary education (40).

### Conclusion

In conclusion, participation is strongly associated with life satisfaction and mental health in the SCI population. Given the results of this study, special attention should be paid to raising the competency of persons living with SCI, in promoting work participation, creating participation opportunities and embarking on further education during post-acute rehabilitation, with follow-up by the rehabilitation team and subsequent care efforts, typically provided in the municipality.

To achieve this, detailed relevant information about the individual's sociodemographic situation needs to be available, together with knowledge on vocational rehabilitation and cooperation with employment advisers, career counsellors and employers. Still, focus on participation in non-vocational activities is required, especially in situations where work reintegration is not relevant or possible. This may be becoming even more important due to ageing in the SCI population, which leads to an increased number of retired persons living with SCI.

Further research is needed into the impact of secondary health conditions and psychological personal factors on changes in participation, e.g. work, before and after SCI, in order to gain further knowledge on which to base advice.

## ACKNOWLEDGEMENTS

The authors thank all the participants who completed the questionnaires, the three SCI specialized centres, located at Haukeland University Hospital, St Olav's University Hospital and Sunnaas Rehabilitation Hospital for registration in NorSCIR, the steering committee of Norwegian SCI registry (NorSCIR) for providing access to the data and Ann Louise Pettersen for providing the data delivery. Thanks are due to Central Norway Regional Health Authority's IT department (Hemit), especially Eilev Hagen, for technical assistance during data collection in the survey. The funding for the research project that this study was part of was provided by the Dam Foundation (grant number 2018/FO198620), the Liaison Committee between the Central Norway Regional Health Authority and the Norwegian University of Science and Technology (NTNU) (grant number 18/420) and the joint research committee between St Olavs hospital HF and the Faculty of Medicine and Health Sciences at NTNU (grant number 2018/42795).

*The authors have no conflict of interests to declare.*

## REFERENCES

1. Fekete C, Siegrist J, Post MWM, Brinkhof MWG, Swi SCISG. Productive activities, mental health and quality of life in disability: exploring the role enhancement and the role strain hypotheses. BMC Psychol 2019; 7: 1.
2. Gupta S, Jaiswal A, Norman K, DePaul V. Heterogeneity and its impact on rehabilitation outcomes and interventions for community reintegration in people with spinal cord injuries: an integrative review. Top Spinal Cord Inj Rehabil 2019; 25: 164–185.
3. Barclay L, McDonald R, Lentin P. Social and community participation following spinal cord injury: a critical review. Int J Rehabil Res 2015; 38: 1–19.
4. Perenboom RJ, Chorus AM. Measuring participation according to the International Classification of Functioning, Disability and Health (ICF). Disabil Rehabil 2003; 25: 577–587.
5. Whiteneck G, Dijkers MPJAopm, rehabilitation. Difficult to measure constructs: conceptual and methodological issues concerning participation and environmental factors. 2009; 90: S22–S35.
6. Piskur B, Daniels R, Jongmans MJ, Ketelaar M, Smeets RJ, Norton M, et al. Participation and social participation: are they distinct concepts? Clin Rehabil 2014; 28: 211–220.
7. The World Health Organization Quality of Life assessment (WHOQOL): position paper from the World Health Organization. Soc Sci Med 1995; 41: 1403–1409.
8. van Leeuwen CM, Kraaijeveld S, Lindeman E, Post MW. Associations between psychological factors and quality of life ratings in persons with spinal cord injury: a systematic review. Spinal Cord 2012; 50: 174–187.
9. Post MW, van Leeuwen CM. Psychosocial issues in spinal cord injury: a review. Spinal Cord 2012; 50: 382–389.
10. Carrard V, Kunz S, Peter C. Mental health, quality of life, self-efficacy, and social support of individuals living with spinal cord injury in Switzerland compared to that of the general population. Spinal Cord 2020; 10.1038/s41393-020-00582-5.
11. van Koppenhagen CF, Post MW, van der Woude LH, de Witte LP, van Asbeck FW, de Groot S, et al. Changes and determinants of life satisfaction after spinal cord injury: a cohort study in the Netherlands. Arch Phys Med Rehabil 2008; 89: 1733–1740.
12. Putzke JD, Richards JS, Hicken BL, DeVivo MJ. Predictors of life satisfaction: a spinal cord injury cohort study. Arch Phys Med Rehabil 2002; 83: 555–561.
13. Muller R, Landmann G, Bechir M, Hinrichs T, Arnet U, Jordan X, et al. Chronic pain, depression and quality of life in individuals with spinal cord injury: mediating role of participation. J Rehabil Med 2017; 49: 489–496.
14. Kent M, Dorstyn DJSC. Psychological variables associated with employment following spinal cord injury: a meta-analysis. 2014; 52: 722–728.
15. van Leeuwen CM, Post MW, van Asbeck FW, Bongers-Janssen HM, van der Woude LH, de Groot S, et al. Life satisfaction in people with spinal cord injury during the first five years after discharge from inpatient rehabilitation. Disabil Rehabil 2012; 34: 76–83.
16. Aaby A, Ravn SL, Kasch H, Andersen TE. The associations of acceptance with quality of life and mental health following spinal cord injury: a systematic review. Spinal Cord 2020; 58: 130–148.
17. Tate DG, Kalpakjian CZ, Forchheimer MB. Quality of life issues in individuals with spinal cord injury. Arch Phys Med Rehabil 2002; 83: S18–25.
18. van Leeuwen CM, Post MW, Westers P, van der Woude LH, de Groot S, Sluis T, et al. Relationships between activities, participation, personal factors, mental health, and life satisfaction in persons with spinal cord injury. Arch Phys Med Rehabil 2012; 93: 82–89.
19. Post MW, van der Zee CH, Hennink J, Schafrat CG, Visser-Meily JM, van Berlekom SB. Validity of the Utrecht Scale for Evaluation of Rehabilitation-Participation. Disabil Rehabil 2012; 34: 478–485.
20. Mader L, Post MW, Ballert CS, Michel G, Stucki G, Brinkhof MW. Metric properties of the Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation) in persons with spinal cord injury living in Switzerland. J Rehabil Med 2016; 48: 165–174.
21. Geyh S, Fellinghauer BA, Kirchberger I, Post MW. Cross-cultural validity of four quality of life scales in persons with spinal cord injury. Health Qual Life Outcomes 2010; 8: 94.
22. Van Leeuwen C, Van Der Woude L, Post MJSC. Validity of the mental health subscale of the SF-36 in persons with spinal cord injury. Spinal Cord 2012; 50: 707–710.
23. Charlifue S, Post M, Biering-Sørensen F, Catz A, Dijkers M, Geyh S, et al. International spinal cord injury quality of life basic data set. J Spinal Cord 2012; 50: 672–675.
24. Biering-Sorensen F, DeVivo MJ, Charlifue S, Chen Y, New PW, Noonan V, et al. International Spinal Cord Injury Core Data Set (version 2.0)-including standardization of

reporting. Spinal Cord 2017; 55: 759–764.

25. DeVivo M, Biering-Sorensen F, Charlifue S, Noonan V, Post M, Stripling T, et al. International Spinal Cord Injury Core Data Set. Spinal Cord 2006; 44: 535–540.
26. 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: 535–546.
27. Fekete C, Eriks-Hoogland I, Baumberger M, Catz A, Itzkovich M, Luthi H, et al. Development and validation of a self-report version of the Spinal Cord Independence Measure (SCIM III). Spinal Cord 2013; 51: 40–47.
28. 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: 596–599.
29. Zurcher C, Tough H, Fekete C, Swi SCISG. Mental health in individuals with spinal cord injury: the role of socioeconomic conditions and social relationships. PLoS One 2019; 14: e0206069.
30. Lund ML, Lexell J. Relationship between participation in life situations and life satisfaction in persons with late effects of polio. Disabil Rehabil 2009; 31: 1592–1597.
31. van Leeuwen CM, Hoekstra T, van Koppenhagen CF, de Groot S, Post MW. Trajectories and predictors of the course of mental health after spinal cord injury. Arch Phys Med Rehabil 2012; 93: 2170–2176.
32. Rivers CS, Fallah N, Noonan VK, Whitehurst DG, Schwartz CE, Finkelstein JA, et al. Health conditions: effect on function, health-related quality of life, and life satisfaction after traumatic spinal cord injury. A prospective observational registry cohort study. Arch Phys Med Rehabil 2018; 99: 443–451.
33. Post MW, Reinhardt JD, Avellanet M, Escorpizo R, Engkasan JP, Schwegler U, et al. Employment among people with spinal cord injury in 22 countries across the world: results from the International Spinal Cord Injury Community Survey. Arch Phys Med Rehabil 2020; 101: 2157–2166.
34. Roels EH, Reneman MF, New PW, Kiekens C, Van Roey L, Townson A, et al. International comparison of vocational rehabilitation for persons with spinal cord injury: systems, practices, and barriers. Topics Spinal Cord Inj Rehabil 2020; 26: 21–35.
35. Gross-Hemmi MH, Post MWM, Bienert S, Chamberlain JD, Hug K, Jordan X, et al. Participation in people living with spinal cord injury in Switzerland: degree and associated factors. Arch Phys Med Rehabil 2019; 100: 1894–1906.
36. Edgerton JD, Roberts LW, von Below S. Education and quality of life. In: Land KC, Michalos AC, Sirgy MJ, editors. Handbook of social indicators and quality of life research. Dordrecht: Springer Netherlands; 2012, p. 265–296.
37. Fekete C, Tough H, Arora M, Hasnan N, Joseph C, Popa D, et al. Are social relationships an underestimated resource for mental health in persons experiencing physical disability? Observational evidence from 22 countries. Int J Public Health 2021; 66.
38. Fekete C, Siegrist J, Reinhardt JD, Brinkhof MW, Swi SCISG. Is financial hardship associated with reduced health in disability? The case of spinal cord injury in Switzerland. PLoS One 2014; 9: e90130.
39. Income and wealth statistics for households. [Internet]. 2021 11.03.21 [cited 2021 May 23]. Available from: https://www.ssb.no/en/inntekt-og-forbruk/statistikker/ifhus
40. Educational attainment of the population. [Internet]. 2020 12.08.2020 [cited 2021 May 27]. Available from: https://www.ssb.no/en/utdanning/statistikker/utniv.